

Running Head: NICU VISITATION AND PARENTAL FEEDING INVOLVEMENT

FACILITATING VISITATION IN THE NEONATAL INTENSIVE CARE UNIT:
EXAMINING THE INFLUENCE OF PARENTAL FEEDING INVOLVEMENT

by

Kelly Semon

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Kelly Semon

Greenville, NC

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Approved by:

Denise Donica, DHSc, OTR/L, BCP

Department of Occupational Therapy, College of Allied Health Sciences

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Introduction

Of every 1000 live births in the United States, approximately 78 newborns will be admitted to a neonatal intensive care unit (NICU) (Harrison & Goodman, 2015). Such units provide highly specialized care to a wide array of newborns in critical condition (Harrison & Goodman, 2015). A NICU may be a Level III or Level IV nursery depending on the level of care provided (Harrison & Goodman, 2015). Traditionally, NICUs utilize an open bay design, housing all of the critical infants in one large room (Pineda et al., 2012). The NICU is often dominated by loud critical care equipment supporting any number of infants in the room (Johnson, 2007). Within this setting, the infant's medical acuity is the primary focus of the entire healthcare team.

Following an extended stay in a NICU, an infant whose health is improving may be transferred to a Level II special care nursery (SCN) before going home (Harrison & Goodman, 2015). Special care nurseries offer a unique environment for parents to bond with their infants while developing their caretaking abilities (Fenwick, Barclay, & Schmied, 2008). The extended length of stay in a SCN allows the healthcare team to focus on nurturing the child and family while ensuring the child's health (Fenwick, Barclay, & Schmied, 2008). Due to the nature of the NICU and SCN, the technology and medicine sustaining the child often overshadows the parental focus of getting to know their newborn (Johnson, 2008). However, throughout their stay in the NICU, infant health outcomes will depend not only on the care provided by medical professionals, but also on the involvement of the baby's biological parents (Davis, Mohay, & Edwards, 2003).

Parental Visitation and Involvement

The past 50 years have seen a proliferation of research studies investigating the

importance of parent-infant relationships for hospitalized children (Davis, Mohay, & Edwards, 2003). This ever-growing body of evidence has come to show that increased parental visitation and involvement results in improved infant outcomes, both immediately in the hospital and long-term (Davis, Mohay, & Edwards, 2003). In response to this information, many hospitals are working to increase parent visitation in the NICU (Johnson, 2008). As hospitals reform policies to better facilitate parental involvement in the NICU, a number of barriers preventing parental involvement have been identified (Wigert, Berg, & Hellström, 2010). The first of these barriers is perhaps the most concrete to parents, the NICU environment itself. The constant advancement of medical technology, while providing lifesaving care, often further isolates the child from the family (Davis, Mohay, & Edwards, 2003). Inability to communicate with the NICU staff or other poor treatment from staff has also been identified as a strong barrier to involvement (Hurst, 2001). Hospital-wide policies, such as restricted visiting hours, heavily influence if and when parents will visit their child (Griffin, 2006). When parents do visit their hospitalized child, extensive restrictions preventing their involvement in care can also limit any future visitation (Hurst, 2001). It is in the best interest of hospitals to continually identify and address these barriers in order to achieve the greatest possible outcomes for their patients (Davis, Mohay, & Edwards, 2003).

All parents are faced with feelings of fear, stress, and confusion when they are separated from their child and their caregiving roles. This is especially true for parents of hospitalized infants (Rossman, Kratovil, Greene, Engstrom, & Meier, 2013). A skilled NICU team can assist parents in overcoming this stress by involving them as much as possible in caregiving activities (Johnson, 2008). Caregiving activities in the NICU can range from

singing to the child to skin-to-skin kangaroo care (Johnson, 2008). This involvement allows parents to develop unique expertise about their child (Hurst, 2001). Over time this expertise allows the parent to more strongly identify as a 'mother' or 'father' to their child (Hurst, 2001). Families with children who are transferred from the NICU to a SCN often experience an increase in caretaking rolls. In the SCN, parents do not only learn more diverse caregiving skills, but they can also take on the roll of directing their child's care (Fenwick, Barclay, & Schmied, 2008). In a study by Wigert, Berg, and Hellström (2010), over a quarter of surveyed parents stated that being invited to participate in care made their presence in the NICU easier.

Feeding Hospitalized Infants

While there are many activities involved in infant care, mothers often feel a unique responsibility for feeding. When a child is admitted to the NICU, parents are typically educated about the value of breast milk for their infant (Rossman, Kratovil, Greene, Engstrom, & Meier, 2013). The provision of breast milk to a child in the NICU can be an empowering action for a parent that also facilitates bonding. The significance of breast milk has been studied extensively, both as a source of healing and as a source of connection (Rossman, Kratovil, Greene, Engstrom, & Meier, 2013). This is not to say that breastfeeding is the only way for parents to provide healing nourishment to their infants. Parents who are unable to provide breast milk can still be involved in their child's feeding rituals. Infant feeding in the NICU is diverse. Nasogastric feeding utilizes a thin tube passed through a nostril of the nose into the throat and down into the stomach to provide nutrition when oral feeding is not yet an option. Bottle-feeding is also utilized for oral feeds, and may contain breast milk, formula, supplement or any combination. When possible,

breastfeeding is the gold standard in the NICU and SCN. These feeding types may be used exclusively, or they may be used in combination (Flacking, Ewald, Nyqvist, & Starrin, 2006). In each of these possibilities for feeding there is opportunity for parental involvement, with or without nursing assistance (Johnson, 2008).

In addition to the invaluable contribution of mother's milk, parental participation in feeding rituals promotes attachment and self-esteem (Flacking, Ewald, Nyqvist, & Starrin, 2006). As parents develop greater confidence in their role as caregivers, the act of attending to their baby's needs may become a stress-reducing experience (Johnson, 2008). The positive psychological outcomes of feeding as well as the bonding between parent and child allow the hospital to become less intimidating and may promote increased visitation (Wigert, Berg, & Hellström, 2010).

Current research has examined the relationship between parental visitation and outcomes for hospitalized infants, as well as the significance of breast milk for infants and their mothers. At this time, there is limited research focusing on the specific occupation of feeding in the NICU. This study is specifically seeking to answer the following question: Do parents who report higher frequency of participation in feeding rituals during NICU or SCN visits also demonstrate an overall higher frequency of visitation than non-feeding parents?

Methods

Research Design

This Honors Project research study is part of a larger longitudinal multi-methods study, which aims to determine the nature of barriers limiting parental visitation and involvement in infant care during the hospitalization of an infant. Parents of infants admitted to the NICU or SCN were asked to complete a questionnaire close to the time of

hospital discharge or unit transfer out of the NICU and/or SCN regarding perceived barriers to visitation, communication within the unit, parent satisfaction with the experience, visitation patterns, and parent emotional factors. Additionally, a medical chart review was conducted on the parent's infant to record further information regarding the pregnancy, infant hospitalization, birth outcomes, therapy records, and parental visitation information.

All participants signed informed consent, including HIPAA authorization, after receiving a thorough explanation of the study during an in-person meeting with a researcher at the study hospital. The study was approved by East Carolina University's University & Medical Center Institutional Review Board (UMCIRB) and all procedures were followed in accordance with the ethical standards of the IRB.

Participants

The study was conducted at a large southeastern hospital, which serves as a regional referral center for high-risk pregnancies. The study setting consisted of the hospital's 50-bed combined level III/ level IV NICU, as well as a 21-bed level II SCN. Biological mothers and self-identified fathers of infants admitted to either unit were recruited via convenience sampling. One of the unit's social workers would share a permission-to-contact card and project flyer with all qualifying parents. Parents were instructed to complete the card and place it in a locked box on the unit if they were interested in participating.

The research project coordinator conducted weekly screenings of all admissions to ensure all parents who contacted and wanted to participate were eligible for the study.

Research team members with current IRB and HIPAA certifications regularly collected the

permission-to-contact cards from a locked box on the unit. Interested parents were contacted by their preferred method to schedule an informed consent meeting. Inclusion criteria for this study consisted of: (1) biological mother or self-identified father of an infant admitted to the NICU or SCN, (2) at least 18 years old, and (3) infant had been admitted for at least 7 consecutive days. Exclusion criteria consisted of: (1) having an infant who was considered terminally ill, (2) having an infant who passed away while hospitalized, (3) being barred from visitation (e.g., due to involvement of Child Protective Services), (4) exclusion at the discretion of the medical team (Gestational Age < 27 weeks), (5) inability to give informed consent due to cognitive capacity and, (6) child was to be put up for adoption.

Instruments

This study utilized two instruments to gather all of the information needed. The majority of the key variables in this study were measured by a self-report questionnaire completed by the parent, which was developed for this study. The remainder of the data was collected via a medical chart review of the hospitalized infant.

Self-report questionnaire. This questionnaire was developed by members of the research team utilizing an array of evidence-based articles to inform item development. This study utilized one section of the questionnaire (“Activities when visiting the NICU / SCN”), visitation data from the medical chart review, and participant demographic information in order to examine the relationship between feeding participation and visitation frequency. Although there are is not yet data regarding the validity and reliability of this instrument, the research team hopes to design a validation study in the near future.

The administration time for this instrument is an average of 10- 15 minutes. The questionnaire is broken into 3 sections, each with distinct subsections.

Section 1: NICU visitation / SCN visitation. The first section of the survey is dedicated to evaluating the parent's experience in the NICU or SCN with regards to visitation. In addition to its subsections, this section also asks the average length of visit for the parent, and whether the parent feels she/he was able to visit as much as desired.

Barriers to visiting. Barriers to visiting are any potential circumstances, feelings, and other factors that may prevent a parent from visiting the infant in the NICU or SCN. Participants responded to 18 items, indicating how applicable each statement was to them on a 5-point Likert scale from "Does not apply at all" to "Applies completely." A sample item for this section would be "I had other children at home to care for."

Activities when visiting. This section lists a number of caregiving activities that parents could be engaged in during their visits to the NICU or SCN. Participants were given a list of 11 common NICU/SCN engagement activities and indicated how often they were involved in each using a 5-point Likert scale from "Never" to "Always." Some activities included in this section were: "Eye contact with the baby," "Bottle-feeding or nasogastric/orogastric tube feeding (with or without nursing assistance)" "Breastfeeding" etc. Participants were also able to input any other activities they participated in which were not listed.

Reasons for visiting. Any personal beliefs or desires that might influence parental visitation were listed in this section. Using a 5-point Likert scale from "Does not apply at all" to "Applies completely," participants responded to 9 items in this section. A sample item for this section is "My baby needed me to be there."

Facilitators to visiting. Circumstances, environmental factors, and positive experiences that may encourage parents to visit the NICU or SCN are listed in this section. Participants responded to 11 items in this section using a 5-point Likert scale from "Does not apply at all" to "Applies completely." A sample item from this section is "The NICU (SCN) staff gave me information about my baby's condition and care when I visited."

Section 2: pregnancy & postpartum thoughts, feelings, behaviors. This section begins by addressing the participant's readiness for their pregnancy. It then goes on to further assess the participant's psychological state following their child's hospital admission.

Ways parents may feel and act. This section of the instrument poses a number of questions regarding parental thoughts, feelings, and actions following their child's birth. To develop the items for this section, the Perinatal PTSD Questionnaire was utilized (Callahan, Borja, & Hynan, 2006). The questions posed focus specifically on thoughts and actions may be indicative of psychological trauma. For each of the 14 questions participants respond using a 5-point Likert scale ranging from "Not at all" to "Very often." A sample item for this section would be "Are you unable to remember parts of your baby's hospital stay?"

Section 3: demographics & background information. The final section of the questionnaire is the demographics section. Parent demographic and background information questions ask about: race/ethnicity, country of origin, number of relatives in the household, history of PTSD symptoms, marital status, education, employment, whether on maternity/paternity leave, and combined household income.

Medical chart review. To supplement the self-report data gathered using the study questionnaire, this research team also performed audits on infant medical charts. To

standardize this process, a medical data form was developed to record the chart data. Due to the nature of hospital charting, the medical data form served primarily as a set of guidelines, as not every item could be located in every participant's records. Information collected about the mother from the infant's chart included: residency information, insurance coverage, pregnancy information (gravidity/parity), and birth information. Information collected about the infant included: demographics, Apgar scores, required medical interventions, hospitalization dates, medical severity information, and discharge information. Following the infant's discharge from the hospital, the researchers returned to the medical chart to extract all of the above indicated data. Data was managed utilizing SPSS Statistics software.

Procedures

Following the consenting process, participants were assigned a study ID number and added to the electronic enrollment log. An eight-digit passcode was also generated for each participant consisting of the last four digits of their phone number and their mother's birth year. Information recorded on the enrollment log included the participant's study ID, study passcode, name, relationship to child, child's name, child's medical record number, and the child's date of transfer or discharge from each unit. Once a participant was added to the enrollment log, the study team was able to begin a preliminary medical chart review. Following the infant's discharge, the full chart review was completed.

During the enrollment process, the research team member would establish a tentative date for survey completion to be confirmed closer to that date. Depending on the duration of the child's NICU stay, the survey was sometimes completed directly after the consenting meeting. Whenever possible, surveys were administered by a member of the

study team at the patient bedside prior to discharge or unit transfer. An online version of the survey was administered via Qualtrics using an iPad or laptop provided by the study team member. Paper versions were also available if requested by the participant. When an in-person administration of the survey was inconvenient for the participant, they were also given the option to complete an online version of the questionnaire from their home computer, complete and return a paper copy, or to complete the survey by phone with a member of the study team. Study passcodes were used to access the survey, eliminating the need for any personal identifying information. Completion of the study questionnaires was scheduled to occur as close to the time of infant discharge or transfer as possible but were required to be completed within 7 days of transfer and 2 weeks of discharge home. This method of scheduling allowed for the participants to answer the survey questions related to the specific unit requested with as much clarity as possible. Additionally, offering the surveys before discharge increased the diversity of respondents to include parents who were heavily involved in their child's care and those who visited infrequently. Each participant received a \$10 Walmart gift card for completing the survey. Participants whose infant was transferred from the NICU to the SCN were given the option to complete the questionnaire a second time at the time of SCN discharge.

Data Analysis

At the conclusion of the data collection phase, all relevant data was gathered for analysis. SPSS Statistics was utilized to create a master spreadsheet and for all data analysis. Variables included on the sheet consisted of study ID, admission and discharge dates, visitation data, and select demographic information from the medical chart review. Additionally, responses from the Qualtrics survey were exported to SPSS directly and items

regarding feeding participation were added to the master file. Descriptive statistics, including means, medians, ranges, and standard deviations were conducted for all continuous variables. Frequencies and percentages were conducted for all categorical variables. Cross tabulations were utilized to differentiate frequencies for maternal and paternal respondents. Using Pearson product-moment correlation calculations, relationships between demographic information, parental visitation, and feeding participation were explored further.

Results

Descriptive Statistics

Participant characteristics. At the conclusion of the data collection phase, a total of 30 participants had been consented, had their infant's chart reviewed, and completed the NICU survey. Among these participants, 20 were mothers and 10 were fathers. Racial distribution was 57% Caucasian and 43% African American. Parent responses indicated that 47% worked full time, 20% worked part time, 17% were unemployed, and 17% were full time students. Of the 5 parents who were full time students, 4 also held a job. While their child was hospitalized, 52% of employed parents took maternity/paternity leave for the entire stay, 32% took leave for part of the child's stay, and 16% took no parental leave. Most study participants were first time parents (50%), or first time NICU parents (30%), while 20% reported having a previous child who was hospitalized.

NICU stay characteristics. The length of stay in the NICU for each participant's infant ranged from 7 days to 62 days ($M = 27.64$, $SD = 16.75$ days). Hospital visitation logs showed that parents visited between 29% and 100% of the days their child was admitted to the NICU ($M = 79.9$, $SD = 22.5$ percent of days). Self-report data indicated that parent

visits to the NICU lasted between 1- 12 hours. The distribution of length of visits to the NICU for mothers and fathers is reported in Table 1.

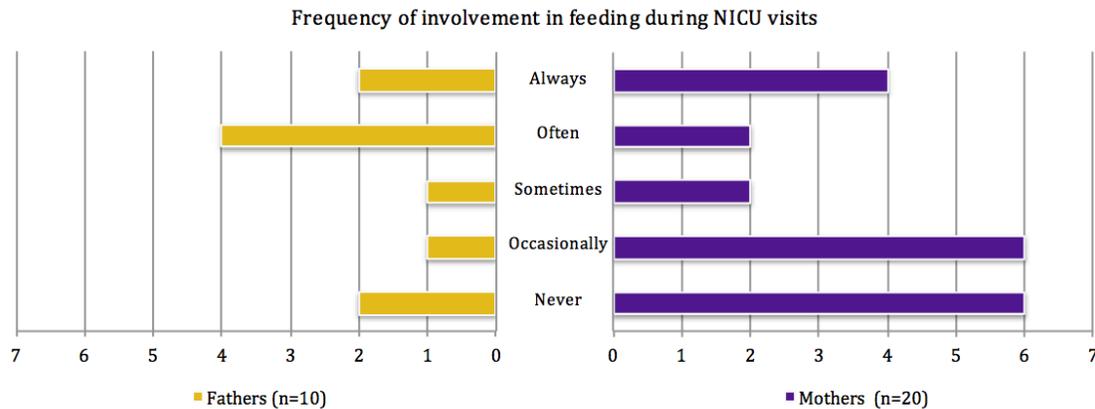
Table 1

Typical Length of Visits – Fathers and Mothers

Length of Visit	Fathers N (%)	Mothers N (%)
1-2 hours	4 (40)	5 (25)
3-4 hours	3 (30)	6 (30)
5-6 hours	2 (20)	3 (15)
7-8 hours	1 (10)	2 (10)
9-10 hours	0 (0)	2 (10)
11-12 hours	0 (0)	2 (10)
Total	10 (100)	20 (100)

The majority of participants reported participating in either breastfeeding, bottle-feeding or nasogastric tube feeding at some point during visits to the NICU. Fathers ($n=8$, 80%) reported slightly more involvement than mothers ($n= 14$, 70%) overall. The frequency of parental feeding involvement over the course of the child's stay is described in Figure 1.

Figure 1
Frequency of involvement in feeding during NICU visits



Correlations and Study Aim

In order to address the study aim, a Pearson product-moment correlation was computed to examine the relationship between frequency of parental involvement in feeding and percentage of days visited during the infant's NICU stay. This relationship between these two variables was determined to be insignificant ($p=.345$ $r= .185$, $n= 28$). A second Pearson product-moment correlation was computed to assess the relationship between frequency of parental involvement in feeding and length of parental visits to the NICU. A moderate positive correlation between the variables was identified and found to be statistically significant ($p=.423$ $r= .020$, $n= 28$).

Discussion

The aim of this study was to determine how parental involvement in feeding during an infant's NICU hospitalization related to overall parental visitation frequency. The majority of parents in the sample group had at least some amount of participation in feeding rituals during the course of their child's stay. Although feeding participation did not

have an effect on the percentage of days parents visited the NICU, findings indicated that parents who reported higher levels of participation were likely to visit for longer periods than those who reported lower levels of participation. This supports Wigert, Berg, and Hellström's earlier finding that parents feel more comfortable in the NICU when included in caregiving.

Limitations & Future Research

This study's primary limitation was the low survey response rate resulting in a smaller sample size. The study was also only able to examine responses from NICU patients, as an insufficient amount of SCN participants completed the survey within the study timeframe. Future research would benefit from a larger sample size as well as the ability to examine data from different nursery types. Future studies would also be strengthened by examining the effects of feeding participation in multiple hospitals, rather than on a single unit.

Within the study sample the mean percent of days visited was much higher than expected for the population. Several participants were able to visit 100% of the days their child was admitted but there was limited representation from parents who visited <30% of days. With a more diverse group of participants, future studies may be better suited to examine the relationship between feeding and visitation rates. Additionally, greater variation in the frequency of feeding participation could further diversify the data set. Broadening the distribution of both variables within the study population could allow for more statistically sound outcomes in future studies.

The nature of charting at the study hospital made it impossible for this study to document the method(s) of feeding each infant was receiving during their NICU stay.

Future studies should plan for a method to acquire this information so that it can be considered as a modulating variable. Within our small sample size, relatively few participants reported breastfeeding during their stay. Larger future studies should aim to examine this group further in comparison to non-breastfeeding parents.

Implications

The value of parental visitation in the NICU has been well documented (Davis, Mohay, & Edwards, 2003). As more and more children are admitted to the NICU each year, it is important for healthcare providers to improve their methods for facilitating visitation (Harrison & Goodman, 2015, Johnson, 2008). While the removal of barriers to visitation will be critical, creating a family centered NICU environment can only further improve visitation rates (Griffin, 2006). Occupational therapists working in NICU settings are in an optimal position to support parental participation as part of the therapeutic process. Including parents in feeding not only allows parents to gain experience performing a crucial skill, but it also encourages them to spend longer periods with their child when they visit the NICU.

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