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## Effect of Anticipatory Guidance on Parental Knowledge and Anxiety Prior to Discharge of Infant from the Neonatal Intensive Care Unit to Home

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Effect of Anticipatory Guidance on Parental Knowledge and Anxiety Prior to Discharge of  
Infant from the Neonatal Intensive Care Unit to Home

Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Nursing  
Practice at the University of Kentucky

By

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Louisville, KY

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## Abstract

**Background:** Lack of adequate parental education and discharge readiness from the Neonatal Intensive Care Unit (NICU) increases the risk for poor infant outcomes, hospital readmissions, postpartum depression, parental anxiety, and post-traumatic stress disorder. One component of parental readiness at discharge is receiving anticipatory guidance from a trusted healthcare provider prior to discharge.

**Purpose/Objectives:** This study aimed to evaluate the effectiveness of provider-led anticipatory guidance to enhance parents' knowledge regarding high-risk infant behaviors and decrease anxiety related to caring for their high-risk infant after NICU discharge. Additionally, this study aimed to assess parental opinions about the value of anticipatory guidance sessions.

**Theoretical framework:** Dorothy Johnson's Behavioral System Model was utilized to guide this research study. This model provides a framework for psychosocial support to NICU parents/caregivers in order to reduce adverse outcomes and hospital readmissions for the high-risk infant.

**Methods:** A quasi-experimental controlled trial utilizing a one group pre-intervention, post-intervention survey design was used to examine the psychosocial effect of anticipatory guidance to parents of high-risk infants nearing hospital discharge from the NICU. Parental knowledge and concerns were assessed using a 5-point Likert scale within seven days of anticipated discharge. The same survey was provided immediately following the anticipatory guidance session to determine its' effectiveness.

**Results:** The mean scores for all elements related to caregiver responsibilities decreased post-intervention, indicating that parental stress and concerns over these elements were decreased after anticipatory guidance was provided. Three elements were statistically significant including:

overall feeding and nutrition goals, breastfeeding goals (if applicable), and who to contact for questions or concerns once discharged home from the hospital. Mean scores for parental stress/concerns over common high risk infant behaviors decreased after the intervention, but not to a significant level. One hundred percent of participants recommended that all NICU families receive anticipatory guidance and deemed the discussion valuable.

**Conclusion:** This study suggested that anticipatory guidance from a healthcare provider decreases parental anxiety and concerns over NICU discharge. Based on the results of this study, it is recommended that parents of high-risk infants receive anticipatory guidance before their infant is discharged.

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## **Dedication**

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## **Background and Significance**

### **Introduction to the Problem**

Technological advances in neonatal medicine have continued to improve survival rates of premature infants at earlier gestations over the most recent 30 years. Since the 1990s, babies as young as twenty-three weeks' gestation have been successfully treated (Stoll et al, 2015) as a result of these advances. The Centers for Disease Control and Prevention (CDC, 2020) reported that 1 out of every 10 births in the United States were affected by prematurity, which is defined as less than 37 weeks' gestation. Preterm infants are breathing and eating prior to a fully developed respiratory and digestive system, requiring medical support that may include endotracheal intubation, parental nutrition, and nasogastric feedings. This advanced technology, along with the infant's behaviors and appearance, result in many parents experiencing stress, anxiety, depression, and fear (Yilmaz et al, 2022). Parents often continue to experience this high stress after discharge (Purdy et al., 2015). Some parents become overwhelmed after hospital discharge due to their high-risk infant's health history, appointments, or requirements to follow-up with healthcare providers who may not be familiar with their infant's medical history and needs (Purdy et al., 2015).

Studies suggest that parents are often unprepared for hospital discharge of their high-risk infant and experience many challenges to adequate discharge education (Balasundaram et al., 2022; Berman et al., 2019; DesMadryl et al., 2021). Following NICU discharge, parents are fully responsible for following through with imperative care regimens (specialized nutrition, medications, follow up appointments, oxygen, and equipment utilization), thus increasing the need for provider-led anticipatory guidance to discuss what home life will be like, and what to expect in terms of their child's care regimens. It is essential that healthcare providers address

topics to parents consisting of preterm birth, feeding problems, bowel habits, sleep routines, developmental delays, and chronic illness (Hagan et al., 2017).

### **Context, Scope, and Consequences**

The main focus of the neonatal providers in the Neonatal Intensive Care Unit (NICU) is improving survival and neurologic outcomes of high-risk infants, and they may not always spend the time necessary to address parental psychosocial needs (Purdy et al., 2015). Parents who are not adequately prepared for discharge with proper education increase the likelihood of readmission, emergency department visits, and unplanned pediatrician visits (Mazur et al., 2021). Additionally, parents require the knowledge needed to continue care once home, along with the ability to cope with their child's medical needs and home life; adequate parent discharge preparedness is essential in improving short- and long-term outcomes of their high-risk infant (Mazur et al., 2021). In order to improve the developmental outcomes of these high-risk infants, as well as family unit function, providers must prioritize the psychosocial support of the NICU parents (Purdy et al., 2015). Anticipatory guidance should be provided at hospital discharge so that parents may have some idea of what to expect at home (Smith et al., 2022). Transition of care from NICU to home will be enhanced by providing education to families about the potential needs of their high-risk infant and anticipatory guidance has consistently been shown to decrease stress (Hsu et al., 2016).

### **Current Evidence-Based Interventions**

Several studies have suggested evidence-based interventions to address the parental anxiety caused by having to care for a preterm infant after hospital discharge and to ensure proper compliance of follow-up appointments. One study found that regular home visits helped to identify and resolve home care errors and common concerns following discharge (Patel et al.,

2017). It is also well documented that classroom education, video instruction, and websites are reasonable methods to increase parents' knowledge and decrease stress ("Solutions for Patient Safety," 2021; Hiscock et al., 2015). During the NICU stay, parents should receive continual nursing and medical support and have questions and concerns addressed immediately by the NICU staff (Wigert et al., 2013).

### **Purpose and Objectives**

Given that parents of preterm infants are at an increased risk of parental anxiety as well as inadequate knowledge of home life expectations—including nutrition, medications, medical equipment, and specialty follow-ups—the purpose of this study was to implement provider-led anticipatory guidance to enhance these parents' knowledge and decrease anxiety related to caring for their high-risk infant after discharge. The following focus of this study:

- Increase parental knowledge of home care of their high-risk infant, i.e., feeding and nutrition expectations, medication regimens, development, and supplemental oxygen.
- Increase knowledge and awareness of specialty follow up appointments.
- Determine the value of anticipatory guidance prior to NICU discharge as perceived by parents and receive their recommendation regarding the practice for other families prior to discharge.

### **Theoretical Framework**

The theoretical framework used to guide this project was Dorothy Johnson's Behavioral System Model. The prospective that Johnson's model for nursing is that humans are an open behavioral system that is interactive and interdependent components with seven subsystems that lead to integration of behavioral health system and the relationship between behavior and

environment. These subsystems include aggressive/protective, eliminative, dependency, affiliative, achievement, ingestive, and sexual (Ghanbari et al., 2018). Johnson's model promotes the facilitation of effective behavioral functioning for illness prevention and emphasizes evidence-based knowledge (TK et al. 2017). One of the goals of Johnson's Behavioral System Model is to assist the individual in benefiting to the maximum extent of the provider's knowledge and expertise. Johnson's belief for nursing was to contribute to the individual's welfare by promoting behavioral functioning in an efficient and positive manner to prevent illness, during illness, and following illness (Alligood, 2022). Utilization of this model for anticipatory guidance prior to NICU discharge provided a framework for educating families about knowledge needed to care for their preterm infant. Adequate discharge preparedness is a modifiable risk factor for preventing hospital readmission in high-risk infants. Therefore, decreasing parental stress is an integral piece of discharge preparedness (Hannan et al. 2020). Providing families with anticipatory guidance prepares them for what to expect of their high-risk infant once discharged in order to prevent future potential stressors and supporting the family unit behavioral function.

## **Review of Literature**

Managing stress and anxiety in parents of NICU infants requires a careful, thoughtful approach. Anticipatory guidance has been shown to be valuable in many pediatric settings including primary, acute, and specialty care. Utilizing the PICO format, the question influencing the literature review for this project was: In families who have an infant in the NICU nearing hospital discharge, does provider-led anticipatory guidance reduce parental anxiety and increase knowledge, facilitating discharge preparedness? A literature search was completed in the CINAHL, PubMed, Ovid, and EBSCOhost databases using the following search terms:

“anticipatory guidance,” “NICU or Neonatal Intensive care discharge,” “anticipatory guidance effectiveness,” “parental stress nearing discharge,” “anticipatory guidance in pediatric population,” and “discharge preparedness.” Reference lists from selected articles were used to identify additional relevant articles. Articles that were published prior to 2011 or did not relate to the pediatric population were excluded from the search, ensuring up-to-date, relevant literature. The final review consisted of 10 articles, originating in primary care (6) and NICU settings (4). Study designs included systematic reviews (2), qualitative studies (4), randomized-controlled trials (2), and expert opinions (2).

The American Academy of Pediatrics (AAP) recommended anticipatory guidance from health care providers as the core of preventive health care (Hagan et al, 2017). Going home with a high-risk infant produces great stress and anxiety in parents. Education regarding care for the high-risk infant will facilitate reduction of this stress and anxiety (Hiscock et al., 2015; Garfield et al., 2014). Parental concerns can be reduced with verbal anticipatory guidance prior to NICU discharge, while at the same time providing psychosocial support (Garfield et al., 2014; Purdy et al., 2015; Smith et al., 2012; Smith et al., 2013). In some cases, parents were given the opportunity to obtain effective anticipatory guidance through brochures/handouts (Hutton, 2017); however, data indicated that parents learn more and are more satisfied with provider-led, verbal anticipatory guidance as they respect and appreciate the advice given from their trusted healthcare provider (Combs-Orme et al., 2011). While handouts and brochures are useful supplements, these materials should be used in conjunction with verbal education.

The AAP also recommended providing anticipatory guidance at each stage of infancy and childhood (Hagan et al., 2017), as this is the foundation for preventive health in children. Currently, in the NICU, education is provided by nursing staff at intervals, but no guidelines or

protocols for anticipatory guidance are shared from a healthcare provider prior to discharge. The AAP suggests counseling parents during the NICU stay and noted that anticipatory guidance should be focused on the parents' concerns and tailored to the specific needs of their child (Hagan et al., 2017). Currently, the research is limited to the effectiveness of anticipatory guidance in the NICU population.

For providers in the NICU follow up clinic, the initial visits with parents are full of questions and concerns about normal variants in preterm infants, growth, development, breathing patterns, specialty follow up visits, and other related concerns. These concerns create anxiety and stress in parents as they attempt to transition home from the NICU stay. It is the obligation of the health care provider to discuss the realities of life at home with a high-risk infant (Smith et al., 2013). This project added to the effectiveness of anticipatory guidance prior to NICU discharge.

## **Methods**

### **Design**

This study used a quasi-experimental one group pre-intervention/post-intervention survey design. This method allowed all available parents for face-to-face dialogue the opportunity to receive anticipatory guidance prior to NICU discharge.

### **Setting**

#### ***Agency Description***

Norton Healthcare is the forerunner in serving the Greater Louisville, Southern Indiana and Kentucky adult and pediatric populations. The setting for this study was Norton Women's and Children's Hospital, a Kentucky leader in infant deliveries, with 6,223 infants born in 2021. The NICU at Norton Women's and Children's Hospital is a Level III, 55 bed unit providing care

for preterm and term infants who need specialized care. All rooms are single family rooms, with 24 private and the remaining semi-private.

At Norton Healthcare, the mission is to provide the highest quality of care to the populations that are served in a process that aligns with the needs of the surrounding communities and honors the organization's faith heritage which consists of the Episcopal Church, The United Methodist Church, the United Church of Christ, and the Roman Catholic Church. The AAP's Bright Futures Guidelines (Hagan et al., 2017) state that it is the responsibility of the pediatric provider to foster the mental health of mothers with counseling and referrals. Providing education to parents about their child's health and development is a critical element and the essence of quality health care, in keeping with Norton's mission.

### **Sample**

The sample size was 15 mothers and/or fathers of infants who were born with less than 36 weeks' gestation, had been in the NICU for at least 7 days, or met criteria for NICU follow up (see criteria listed in Appendix A). Participants were also available for face-to-face discussion and agreeable to participation in the study.

### **Procedures**

#### ***IRB Approval***

Prior to the study, Institutional Review Board (IRB) approval was obtained from the University of Kentucky's Medical IRB as well as Norton Healthcare for the study taking place at Norton Women's and Children's Hospital. Data were obtained through anonymous survey responses without the possibility of determining individual participants' identities and were stored on firewall protected and encrypted computers linked to the Norton Healthcare internal server.



### ***Evidence-Based Intervention***

The intervention included face-to-face dialogue, or anticipatory guidance, where the principal investigator shared information with parent(s) or other caregivers about what to expect in their child's next phase of development (Benson, 2020). Anticipatory guidance included information about overall feeding and nutrition goals, medication regimens, use of oxygen equipment/feeding pumps (if applicable), specialty follow-up appointments, and resources for questions regarding nutrition, development, medications, or equipment. Furthermore, education concerning high-risk infants' bowel habits, sleep routines, breathing patterns, and overall development and milestone achievements were discussed.

### ***Measures and Instruments***

A pre-intervention and post-intervention survey was created by the principal investigator and refined by an expert panel consisting of an attending neonatologist, a NICU pediatrician, and an advanced practice nurse in the NICU follow up clinic. The survey was designed to meet the specific criteria regarding anticipatory guidance prior to NICU discharge as outlined by the AAP. The survey included 19 total items consisting of demographic information, items that measured parental stress/concerns over common responsibilities once discharged home from the hospital, and parental stress/concerns over common high-risk infant behaviors. Demographic items (7) consisted of: relationship to infant, age, ethnicity, marital status, educational level, ethnicity, race, and number of children in the home (including the NICU infant). Parental stress and concerns over common caregiver responsibilities once discharged were measured by 7 questions based on a 5-point Likert scale (1 = not at all concerned or stressed – 5 = extremely concerned or stressed). These responsibilities included: 1) Feeding and nutrition; 2) Breastfeeding; 3) Medication regimen; 4) Durable medical equipment (if applicable); 5) Follow up appointments;

6) Who to contact for questions; and 7) Overall feeling of stress about discharge. Five questions regarding parental stress/concerns over common high-risk infant behaviors also were assessed by a 5-point Likert scale (1 = not at all concerned or stressed – 5 = extremely concerned or stressed). Those behaviors included: 1) Bowel habits; 2) Sleep patterns; 3) Overall growth; 4) Breathing patterns; 5) Development and milestones. Comparable survey questions and items have been utilized in prior studies (Khalesi et al., 2015., Owens et al., 2011, McGowan et al., 2017). Two questions were included at the end of the survey that were focused on the value of anticipatory guidance from the perspective of participants and included: “Do you feel the information session from a NICU follow up provider prior to hospital discharge was helpful?” and “Would you recommend all NICU families have this information session prior to hospital discharge?” Participants had the option of “yes,” “no,” and “I am not sure.”

### ***Data Collection***

The principal investigator attended weekly discharge planning meetings with the NICU discharge planner and attending neonatologists, where potential participants were identified. Parents and caregivers of infants who were within one week of anticipated discharge were recruited and a predetermined timeframe for meeting at their child’s bedside was established. After parents were enrolled and consent was obtained for the study, the survey was given by the principal investigator via iPad with link to the Research Electronic Data Capture system (REDCap) survey. Participants were given 30 minutes to complete the pre-intervention survey. Immediately following the pre-intervention survey, the provider led anticipatory guidance intervention was completed. Immediately following the interventions, participants were given an additional 30 minutes to complete the post-intervention survey. Pre-intervention surveys and

post-intervention survey data were transferred to data analysis software for further evaluation of outcomes.

### ***Data Analysis***

Descriptive statistics were used to summarize participant demographic characteristics, via frequency distribution. Differences between the 12 pre-intervention and post-intervention survey items were assessed using a paired t-test. Frequency distribution was used for analysis of parental recommendation and usefulness of the intervention. SPSS version 27 was used to perform statistical analysis. Statistical significance was considered a p-value less than or equal to 0.05.

## **Results**

### **Sample Characteristics**

Fifteen parents/caregivers participated in the study. The most frequently reported age was 32-37 (50.0%), followed by 24-31 (28.6%; see Table 1). The majority of participants were mothers (66.7%) with the remaining being fathers. Participants in the study were comprised of 80% married and the remaining single, never married. The majority (50%) had some college education, followed by 33.3% having an undergraduate college degree. The most frequently reported race was White (53.3%), followed by Black or African American (26.7%). Most of the participants (40%) had one other child in addition to the infant in the NICU, while 26.7% did not have any other children.

### **Parental Stress/Concerns Over Caregiver Responsibilities**

The mean scores for all elements related to caregiver responsibilities decreased post-intervention, indicating that parental stress and concerns over these elements were decreased

after anticipatory guidance was provided. Three of the items had a statistically significant decrease: overall feeding goals and nutrition, breastfeeding goals, and who to contact for questions once discharged. The mean for overall feeding goals and nutrition was 2.27 (SD = 1.33) in the pre-intervention survey compared to a mean of 1.47 (SD = 0.83,  $p = 0.04$ ) in the post-intervention survey. The pre-intervention survey mean for achieving breastfeeding goals was 2.54 (SD = 1.5) and the mean for post-intervention survey was 1.54 (SD = 0.66,  $p = 0.04$ ). Lastly, the mean score for resources and who to contact for questions once discharged was 1.87 (SD = 1.40) in the pre-intervention survey and 1.0 (SD = 0.00,  $p=0.03$ ) in the post-intervention survey. There was a modest decrease in the score for overall feelings of stress about hospital discharge (M = 1.67, SD = 1.23) in the pre-intervention survey and a mean of 1.0 (SD = 0.00,  $p = 0.06$ ) in the post-intervention survey. See Table 2 for further details about the change in parental stress and concerns over caregiver responsibilities pre- and post-intervention.

### **Parental Stress/Concerns Over Common High-Risk Infant Behaviors**

Although the mean stress/concern scores for all common high-risk infant behavior items decreased after the intervention, there was no statistical significance between the pre- and post-survey scores. These scores represent some decrease in parental stress and concerns over common high-risk infant behaviors. Scores regarding development and milestone achievements decreased modestly, from a mean of 2.33 and an SD of 1.40 in the pre-intervention survey to a mean of 1.67 (SD=0.90,  $p = 0.06$ ) in the post-intervention survey. See Table 3 for more details about the change in stress and concerns over common high-risk infant behaviors from pre- to post-intervention.

## Value of Anticipatory Guidance

One hundred percent of participants reported that the anticipatory guidance with a NICU follow-up provider prior to discharge was helpful. Likewise, 100% of respondents recommended that all NICU families have anticipatory guidance prior to hospital discharge.

## Discussion

The purpose of this study was to evaluate the effect of pre-discharge anticipatory guidance on parental stress and concerns, and to determine whether NICU families would recommend and find such guidance valuable. Overwhelmingly, participants recommended anticipatory guidance and deemed the discussion valuable. The fact that there was an overall decrease in stress scores pre- and post-intervention is consistent with the results of other studies on the effectiveness of anticipatory guidance in the pediatric population (Garfield et al., 2014; Hiscock et al., 2015; Hutton et al., 2017; Hsu et al., 2016; Purdy et al., 2015; Smith et al., 2012; Smith et al., 2013). For example, Hsu et al. (2016) found that guidance from a healthcare provider was consistently associated with lower stress in mothers of infants and young children. Anticipatory guidance prior to discharge facilitates readiness in parents of NICU infants by decreasing the overall anxiety and concerns over their home life expectations (Smith et al., 2012; Smith et al., 2013). This study confirms that parents need face-to-face discussions with their child's healthcare provider prior to NICU discharge to help them develop a realistic view of their home life with their high-risk infant.

It is important to note that at the time of this study, there was a national shortage of infant formula; this could have falsely heightened parents' stress and concerns over hospital discharge

and nutrition requirements. Future research should focus on the long-term benefits of anticipatory guidance prior to NICU discharge. Pre-intervention stress scores were relatively low, perhaps related to caregivers being unfamiliar with their infants' behaviors prior to taking on full-time, sole responsibility for their care. The results of this study are an important consideration when determining the value of anticipatory guidance prior to NICU discharge.

### **Implications for Practice, Education, Policy, and Research**

As the AAP has recognized, parents and caregivers who are nearing hospital discharge with a high-risk infant require reassurance from their trusted healthcare providers. Providers who have been caring for NICU infants have been present since the day of birth, and families come to trust their opinions and expertise. Hospital administration should allow for adequate provider staffing to ensure that all families have the opportunity to receive anticipatory guidance from the provider, within seven days of hospital discharge.

Further research is needed to determine the long-term benefits of anticipatory guidance. Many families are not aware of the common high-risk infant behaviors until they are discharged home and with their child on a full-time basis. This is when caregivers observe their high-risk infants' bowel habits, breathing patterns, and sleep routines differ from their full-term counterparts. Researchers have the potential to study the benefits of anticipatory guidance at the initial NICU follow-up appointment, approximately two weeks after discharge.

Researchers should also focus on which families would benefit most from the anticipatory guidance based on hospital diagnosis and length of stay. There are a wide variety of diagnoses in the NICU, requiring various lengths of stay. Further studies could be conducted to determine if parents of infants who had a longer NICU stay would benefit more or less from anticipatory guidance than parents whose infants spent less time in the unit. Likewise, further

research could examine socioeconomic influences on parental stress levels and concerns and the effectiveness of anticipatory guidance.

### **Limitations**

There were several limitations to the study, the first being a small sample size due to time constraints. The period for data collection was reduced to two months from the planned six months. Parents and caregivers were required to be at the child's bedside for study enrollment and since most parents had other children at home, their time in the NICU was limited. Additionally, parents who were at the bedside for the study were typically there for their child's "care time," during which they were responsible for hygienic care and feedings. This could have resulted in distraction during the surveys and anticipatory guidance discussions.

Another possible limitation was the use of a non-validated instrument, despite it having been expertly reviewed. This instrument was developed by the principal investigator and the items included were the most common concerns from families at NICU follow-up appointments. Many of these same items were recommended by the AAP for anticipatory guidance prior to NICU discharge, so although the instrument has not yet been validated, it is based on a solid body of evidence.

An unforeseen limitation to the study was the national shortage of formula. This phenomenon was not anticipated, so it was not addressed during the survey development, despite being an additional stressor for parents who depend on specialty formulas for their high-risk infants. Lastly, the lack of previous research on the effectiveness of anticipatory guidance prior to NICU discharge was a limitation.

## **Conclusion**

Anticipatory guidance from a healthcare provider within seven days of hospital discharge appears to decrease overall stress and concerns from parents regarding their responsibilities and high-risk infant behaviors. The parents and caregivers in this study deemed the discussion valuable and recommended that all families who are nearing hospital discharge receive this guidance. These results support the need for hospital administration to adequately staff providers in the NICU to allow for all families to have a face-to-face discussion about what to expect once they are home with their high-risk infant. Further research is needed to determine the long-term effectiveness of anticipatory guidance.



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## Tables

**Table 1: Demographic Information for participants (N=15)**

Characteristic	<i>n</i> (%)
Age	
18-23	1 (7.1%)
24-31	4 (28.6%)
32-37	7 (50.0%)
38-43	2 (14.3%)
Relationship to patient	
Mother	10 (66.7%)
Father	5 (33.3%)
Marital status	
Single- never married	3 (20%)
Married	12 (80%)
Level of education	
High School/GED	1 (8.3%)
Some College	6 (50%)
College Graduate	4 (33.3%)
Masters/Doctoral	1 (8.3%)
Ethnicity	
Not Hispanic or Latino	0 (100%)
Race	
Asian	3 (20%)
Black or African American	4 (26.7%)
White	8 (53.3%)
Children living in the home	
1	4 (26.7%)
2	6 (40%)
3	1 (6.7%)
4	2 (13.3%)
5	1 (6.7%)
6 or more	1 (6.7%)

**Table 2: Changes in parental stress/concerns over parental responsibilities pre and post intervention (N=15)**

Caregiver Responsibility	Pre-intervention <i>Mean (SD)</i>	Post-intervention <i>Mean (SD)</i>	<i>p</i>
Overall feeding goals	2.27 (1.33)	1.47 (0.83)	0.04
Breast-feeding goals	2.54 (1.5)	1.54 (0.66)	0.04
Medication regimen	2.27 (1.61)	1.0 (.00)	0.26
Use of DME	3.50 (1.91)	1.25 (0.50)	0.12
Follow up	1.54 (1.13)	1.0 (.00)	0.11
Who to contact	1.87 (1.40)	1.0 (.00)	0.03
Overall stress	1.67 (1.23)	1.0 (.00)	0.06

Note: Responses follow a Likert-scale ranging from 1) ‘Not at all concerned’ to 5) ‘Extremely concerned’

**Table 3: Changes in parental stress/concerns over common high-risk infant behaviors pre and post intervention (N=15)**

Infant Behavior	Pre-intervention <i>Mean (SD)</i>	Post-intervention <i>Mean (SD)</i>	<i>p</i>
Bowel habits	1.6 (1.12)	1.2 (0.56)	0.19
Sleep routine	1.8 (1.08)	1.27 (0.46)	0.09
Overall growth	2.27 (1.33)	1.67 (0.90)	0.08
Breathing patterns	1.87 (1.41)	1.33 (0.82)	0.12
Development	2.33 (1.40)	1.67 (0.90)	0.06

Note: Responses follow a Likert-scale ranging from 1) ‘Not at all concerned’ to 5) ‘Extremely concerned’

## Appendix A

### **Criteria for NICU follow-up**

Infants born less than 36 weeks' gestation

Infants born less than 1500 grams

Need for supplemental oxygen after discharge

Concern for feeding difficulties post discharge

Gastronomy or Nasogastric tube dependent

In utero drug exposure

Increased calories of 24 kcal/oz or higher

Known or suspected genetic disorders

Hypoxic Ischemic Injury

Intraventricular hemorrhage

Periventricular leukomalacia

## Appendix B

### Survey Focused on Parental Responsibilities and Common High-risk Infant Behavior

Page 2

**Listed below are some of the responsibilities you will take on once your high-risk infant is discharged from the NICU. These responsibilities are known to cause caregivers concern and/or stress. Fill in the number that best represents your level of concern or stress about the responsibilities.**

	Not Applicable (NA)	Not at all concerned or stressed	A little concerned or stressed	Moderately concerned or stressed	Very concerned or stressed	Extremely concerned or stressed
8) Your infant's overall feeding goals and nutrition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) Achieving your breast-feeding goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) Your infant's medication regimen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) Use of the oxygen equipment or other durable medical equipment (i.e. home nebulizer or feeding pump)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) Specialty follow-up appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) Who to contact for questions regarding your infant's feedings, medications, and/or medical equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14) Your overall feeling of stress or concern about hospital discharge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Listed below are some infant behaviors that are known to cause caregiver concern and/or stress once the infant has been discharged from the NICU. Fill in the number that best represents your level of concern or stress about the behaviors.**

	Not at all concerned or stressed	A little concerned or stressed	Moderately concerned or stressed	Very concerned or stressed	Extremely concerned or stressed
15) Your infant's bowel habits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16) Your infant's sleep routine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17) Your infant's overall growth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18) Your infant's breathing pattern and/or oxygen levels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19) Your infant's overall development and milestone achievements	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

06/14/2022 5:14pm

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