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## Effect of a Parent Empowerment Program on Length of Stay and Parental Stress in the Neonatal Intensive Care Unit

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The document mentioned above has been reviewed and accepted by the student's advisor, on behalf of the advisory committee, and by the Assistant Dean for MSN and DNP Studies, on behalf of the program; we verify that this is the final, approved version of the student's DNP Project including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

Holly L. Nieves, Student

Dr. Leslie Scott, Advisor

DNP Final Project Report

Effect of a Parent Empowerment Program on Length of Stay and Parental Stress in the Neonatal  
Intensive Care Unit

Holly L. Nieves

University of Kentucky

College of Nursing

Fall 2017

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## Dedication

This DNP project is dedicated to my five boys, Logan, Drew, Evan, Bryson and Jack, who have supported and encouraged me throughout this process. They have shown me amazing understanding and grace during the three and a half years during this program. They have had unbelievable patience for the demands of obtaining a doctoral degree. They certainly are my biggest cheerleaders. And to my parents who have always done whatever it takes to ensure my success in life and in the DNP program. They have made daily sacrifices to help my boys and I through what has been a very difficult yet inspiring year.

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Introduction to Final DNP Project

Holly Nieves

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In the United States, there are approximately 380,000 infants born prematurely each year, which equals roughly 9.6% of live births (Hamilton, Martin & Osterman, 2016). Since the 1980's, advances in Neonatal Medicine has allowed extremely premature infants to survive, however morbidity remains high, creating a financial and emotional burden on parents and the healthcare system (Melnik et al, 2006). Premature infants suffer a host of health problems while in the hospital including renal complications, respiratory distress, sepsis, intraventricular hemorrhages, retinopathy of prematurity, feeding intolerance and poor growth (Abitbol & Rodriguez, 2012; McCormick, Litt, Smith & Zupancic, 2011). The health system experiences a cost burden with this population, as the average cost of a preterm hospitalization is approximately \$1,250 to \$2,000 per day (Melnik et al., 2006). The average stay in the NICU is 25 days, with an estimated cost of \$30,527 for an infant born at 32 weeks gestation (Kirby, Greespan, Kornhauser & Schneiderman, 2007). After discharge, neonatal morbidities continue into the newborn, preschool, school-age and adulthood periods, which include hospital readmissions for respiratory distress, neurodevelopmental delays, intellectual disability, behavioral issues, and mental disorders (McCormick, Litt, Smith & Zupancic, 2011).

The Effect of a Parent Empowerment Program on Length of Stay and Parental Stress in  
the Neonatal Intensive Care Unit

Holly Nieves

University of Kentucky

## **Background**

The Institutes of Medicine calculated that the annual cost of prematurity in the United States is greater than 26 billion dollars with the estimated hospitalization costs of 16.9 billion dollars (McCabe, Carrino, Russell & Howse, 2014). Length of stay and cost of hospital days have been scrutinized for several decades. To reduce this burden, and increase neonatal outcomes, many approaches have been researched to decrease length of stay: delayed cord clamping (Mercer et al., 2006), fluconazole prophylaxis preventing candida infections (Kaufman & Manzoni, 2010), antibiotic stewardship to decrease bloodstream infections (Cantey & Milstone, 2015), use of new diagnostic tool to detect sepsis (Brozanski, Jones, Krohn & Jordan, 2006), use of donor breast milk (Kantorowska, Wei, Cohen, Lawrence, Gould & Lee, 2016), incubator weaning (Schneiderman, Kirkby, Turenne & Greenspan, 2008), and standardized documentation (Butler, Firestone, Grow, & Katak, 2013).

In addition to the morbidities experienced by the premature infant, the parents also endure extreme stress, fatigue, feelings of helplessness, poor parent-infant bonding, knowledge deficits, depression, and anxiety (Jubenville, Newburn-Cook, Hegadoren & Lacaze-Masmonteil, 2012; Chertok, McCrone, Parker & Leslie, 2014). These adverse experiences may ultimately affect the way parents care for their infant, the length of hospitalization, the overall health of the infant, hospital readmission rates, long-term cognitive development of the child, and increased hospital expenditures (Melnik et al., 2006). Thus addressing ways to mitigate these problems is important to families and the health care system.

## **Purpose**

To address parent empowerment and the impaired parent-infant dyad due to the stressful NICU environment, neonatal intensive care units can implement clearly defined empowerment and education programs for parents of premature infants to enhance interaction, bonding, knowledge, and facilitate the discharge process. Several variations of parent empowerment programs have been examined including: a 2-phase parent-teaching program (Abdeyazdan, Shahkolahi, Mehrabi & Hajiheidari, 2014), individualized parental intervention by psychologist (Gimenez & Sanchez-Luna, 2015), multi-media programs that are nurse driven (Melnyk et al., 2006; Borimnejad, Mehrnoosh, Fatemi & Haghani, 2013), and a parent group program (Bracht, O'Leary, Lee & O'Brien, 2013). These programs all conclude that providing parental empowerment programs decreases parental stress and increases empowerment.

The Creating Opportunities for Parent Empowerment (COPE) program developed by Bernadette Melnyk provides parental education and empowerment material during the NICU stay in a mixed media format by print and audiotapes. This program is grounded in the self-regulation theory (Johnson, Fieler, Jones, Wlasowicz, & Mitchell, 1997), and the control theory (Carver, 1979), as cited in Melnyk et al., 2001. Melnyk's program has been replicated and shown to decrease parental stress and length of stay in the United States and Iran (Melnyk et al., 2006; Mianaei, Karahrudy, Rassouli, & Tafreshi, 2014; Gonya, Martin, McClead, & Shepher, 2014).

The goal of this project was to implement the COPE for HOPE program in the level three NICU at Baptist Health Lexington and evaluate parental stress, postpartum depression, parental

satisfaction and length of stay before and after implementation. The following objectives were the main goals of the study:

- 1.) Measure parental stress in parents of premature infants less than 35 weeks, before COPE implementation and after implementation, using the Parental Stressor Scale: NICU (PSS: NICU) (Miles, 2011).
- 2.) Measure maternal depression in moms of premature infants less than 35 weeks using Edinburgh Postnatal Depression Scale (EPDS) before COPE implementation and after implementation (Cox, Holden & Sagovsky, 1987).
- 3.) Measure length of stay in both groups, before and after COPE implementation.
- 4.) Measure parent satisfaction using the Baptist Health Lexington NICU scale at 2-4 weeks after discharge in both pre-implementation and implementation groups.

## **Methods**

There were two cohorts in this study. Both cohorts were selected using the same inclusion/exclusion criteria (Table 1).

The first cohort included parents enrolled between April 1<sup>st</sup> and June 30<sup>th</sup>, 2017. Parents who met the criteria were approached by the principal investigator and offered to take part in the study. If consent was obtained, the PSS: NICU, EPDS, Baptist Health Lexington Parent Satisfaction Survey, demographic data, and length of stay were collected at certain time frames during the hospitalization (Table 2).

The second cohort in this study began enrolling parents July 1<sup>st</sup> and finished enrolling parents September 10<sup>th</sup>, 2017 using the same inclusion/exclusion criteria. Parents who

met this criterion were approached and offered to take part in the study. The principal investigator of the study obtained consent. If consent was obtained, the same surveys in the pre-intervention cohort were completed as well as the four COPE for HOPE parent empowerment phases (Table 3).

The COPE for HOPE parent training and education phases were completed at the bedside by specially trained COPE champion nurses. These nurses, before the intervention cohort started, completed a one-day Cope for Hope parent empowerment training session lead by Cope for Hope staff member along with the principal investigator. All other nurses in the NICU were given written training materials on the parent empowerment programs so they were familiar with the education and could reinforce what had been taught. Each COPE training session with parents included teaching and activities that focused on increasing parent knowledge, decreasing stress, and increasing parental confidence in parent-infant interactions.

## **Setting**

Baptist Health is a large healthcare organization throughout Kentucky and southern Indiana. This program was implemented at Baptist Health Lexington in Lexington, KY. This is a level 3 NICU with single patient rooms, with the ability to hold up to 32 babies. This NICU admitted 413 babies in 2016. 58% or 240 of those admissions were premature infants less than 35 weeks. In addition to the nursing staff, the NICU has a dietician, physical therapists, occupational therapists, speech and language therapists, an educator, neonatologists and neonatal nurse practitioners, social workers, lactation and chaplains.

## **Sample**

To examine the effect of the parental empowerment program, the pre-intervention cohort was selected based on a convenience sample. This sample consisted of all babies who were born less than 35 weeks, in the time frame allocated, met inclusion/exclusion criteria, and who consented to participate. The intervention cohort also included a convenience sample including all babies born before 35 weeks and after the intervention was implemented, who met inclusion/exclusion criteria, and who also consented to participate. The sample consisted of 29 parent sets in the pre-intervention group and 20 parent sets in the intervention group.

## **Data Collection**

Approvals from the University of Kentucky Institutional Review Board and the Baptist Health Lexington Institutional Review Board were obtained prior to the start of the study and the collection of data. After parent sets were enrolled in the study, surveys were given to parents at predetermined timeframes during the infant's hospitalization (See attachments 1-3). Either the principal investigator or the COPE nurses would initiate and collect the surveys from the parents. In addition to surveys, the parents also completed a demographic sheet before discharge. Length of stay was collected from the electronic medical record after discharge.

## **Primary Measure Outcomes**

To assess parental stress in the NICU, the Parental Stressor Scale: NICU (Miles, 2011) (Attachment 1) was used. This scale has an established construct validity and measures parental stress in 3 dimensions including: 1. Sights and sounds in the NICU; 2. Infant behavior, appearance and treatments; and 3. Parental role alteration. Parents scored their perceived stress on 26 items using a 5 point Likert scale ranging from 1 (no stress) to 5 (extremely stressful). A

higher total score indicated a greater stress level. This survey was given to parents during the first 2 to 4 days of admission into the NICU in both pre-intervention and intervention groups.

Maternal depression was assessed using the Edinburgh Postnatal Depression Scale (EPDS) (Attachment 2) (Cox, 1987). This scale measures postpartum depression in a 10-question survey and indicates how a mother has been feeling during the previous week. The scale has a maximum score of 30 with possible depression in scores of 10 or greater. The questions are designed using a 4 point Likert scale ranging from 0 to 3. This survey was given to mothers 1 to 7 days before their baby's NICU discharge in both pre-intervention and intervention groups.

Parent Satisfaction was measured in both pre-intervention and intervention groups using the Baptist Health Lexington Parent Satisfaction Survey (Attachment 3). This survey was completed 2-4 weeks after discharge by Baptist Health Lexington NICU nurses who placed telephone calls to parents. The survey is a 5 question, 5 point Likert scale survey which measures parental satisfaction with the NICU stay. The survey asks satisfaction questions in regards to the nursing staff, the physician staff, the environment, communication, and preparation for discharge and overall quality of care.

To assess length of stay, the electronic medical record was used for birth date and discharge date. Demographics (Figure 4) of the parents were obtained using a form completed by parents before discharge. This form asked parents age, education level, occupation, and marital status.



## **Data Analysis**

Descriptive statistics, including frequency distributions, means, and standard deviations were used to describe patients' demographic characteristics as well as parent characteristics. Continuous variables were compared using the Independent Sample *t*-tests. All analysis was conducted using SPSS version 23; an [*alpha*] level of .05 was used for statistical significance throughout.

## **Results**

### **Sample Characteristics**

There were a total of 29 parent sets in the pre-intervention group and 20 parent sets in the intervention group. For parents with multiples, the length of stay for the baby with the longest hospitalization was used for length of stay calculations. In the pre-intervention group, a set of twins were transferred out to a level 4 NICU and two infants in the intervention group were transferred out to a level 4 NICU; therefore, the total pre-intervention sample was 28 and the intervention sample was 18.

The demographics of the pre-intervention group and the intervention group were strikingly different. In the pre-intervention group, 48.3% of the infants were male and 51.7% were female. In the intervention group 75% of the infants were male and 25% were female. In addition to gender differences, there were also gestational age differences between the two groups. The mean gestation of the pre-intervention group was 33.28 weeks and the mean gestation of the intervention group was 31.89 weeks (See table 4).

To determine significance between the two groups, a chi square analysis was used to compare gender. There was no statistical difference found between the groups in gender with a

chi square statistic of 3.4996 and p of 0.061. To compare gestation between the groups an independent t-test was conducted. There was a significant difference between gestational age in the pre-intervention group (M=33.28weeks, SD=1.47) and intervention group (M=31.89weeks, SD=2.14;  $t(31.13)$ ,  $p=0.017$ ). With this statistical difference between the two groups, the intervention phase is known from the literature to be at a disadvantage when examining length of stay, morbidities and mortality.

### **Length of Stay**

An independent-samples t-test was conducted to compare the length of stay between the pre-intervention and intervention groups. There was no significant difference in length of stay between the pre-intervention group (M=24.21 days, SD=15.69 days) and intervention group (M=31.61 days, SD=15.71 days;  $t(44)$ ,  $p=0.126$ ). After examining the differences in the group, this length of stay result was not

### **Parental Stress**

There were 27 parent sets who completed the PSS:NICU in the pre-intervention group and 19 parent sets in the intervention group. There was a significant difference in parental stress between the pre-intervention group (M=63.07, SD=26.4) and intervention group (M=48.36, SD=21.1;  $t(44)$ ,  $p=0.050$ ).

A one-way between groups analysis of variance was conducted to explore the impact of the COPE program on the parental role as measured by the PSS: NICU. There was a statistically significant difference at the  $p<0.05$  level in parental role score for the pre-intervention compared to the intervention group with a p value of 0.034.

## **Maternal Depression**

For the Edinburgh Depression Scale, 23 moms completed the survey in the pre-intervention group and 16 completed the survey in the intervention group. Although the intervention group overall mean was lower than the pre-intervention group, there was no significant difference between the pre-intervention group (M=6.69, SD=4.19) and the intervention group (M=4.12, SD=4.08,  $t(37)$ ,  $p= 0.065$ ).

## **Parental Satisfaction with the NICU**

The parent satisfaction scores were completed on 27 total parent sets. 100% of all the parents in both groups answered five, being most satisfied on four of the five questions. One parent set answered a four on the nurse communication question, where all other parent sets answered a five. These outcomes, with almost perfect results in both cohorts show no differences between the two groups in parental satisfaction with the NICU.

## **Discussion**

This study aimed to better understand the impact of the COPE for HOPE program on length of stay, parental stress, maternal depression and parental satisfaction in the neonatal intensive care unit. Demographic differences in the pre-intervention group and intervention group could give insight into the length of stay results of the study. However, there were important significant results indicated in this study, which has also been seen in other studies, related to parental stress. This significance is important to acknowledge and consider as components of care in the neonatal intensive care unit.

## **Length of Stay and Differences in the Groups**

There were significant differences in the pre-intervention and intervention groups of this study including related to the gestation of the groups. The difference in gestation of 33.28 weeks in the pre-intervention and 31.89 in the intervention group is significant in this population as far as mortality and morbidity and length of stay in the NICU. Survival significantly increases with every week of increase in gestational age (Glass et al., 2015). For this study, there was a statistically significant difference between the two groups in gestational age. In addition to gestation, gender has also been found as a major determinant for morbidity and mortality in the NICU population (Ito, Tamura & Namba, 2017). The intervention group was predominately white males who were younger in gestation than the pre-intervention group. The pre-intervention group was also predominately white, however, there was a near equal mix of males to females. Although no significance was found in gender, the literature reports that male premature infants are at a meaningful disadvantage compared to their female counterparts born at the same gestation (Ito, Tamura & Namba, 2017). These differences in the groups, in addition to the small sample size, could be argued as the reason for the increase in length of stay between the two groups.

## **Parental Stress**

Parental stress was measured using the PSS: NICU. This tool, with built-in subscales, has been used for decades and has been shown to longitudinally predict depressive symptoms of mothers of premature infants (Miles et al., 2007). In this study the PSS: NICU scores were statistically significantly lower in the intervention group. There was also a statistical significance between the two groups in relation to the parental role subscale. This result is a noteworthy insight to neonatal nursing practice. With implementation of the COPE for HOPE

program, the parents in the intervention group felt less stress about the NICU environment, the way their baby looked and behaved and treatments in the NICU. More specifically the parents were significantly less stressed about the separation from their infant in the NICU, not being able to feed their infant, not being able to care for their baby, not being able to hold their baby, less feelings of helplessness, and not having alone time with their baby.

### **Maternal Depression**

Although not statistically significant, the maternal depression scores in the intervention group were lower than those in the pre-intervention group. Again, there may have been statistical significance found with a larger sample size.

### **Parental Satisfaction**

Parental satisfaction was the same across the two groups of this study. Both groups consistently answered a 5 on all the questions. However, one parent did answer a 4 on one question related to nurse communication. These homogenous results indicate that the survey may not be an effective way to measure parent satisfaction as no difference was found within or between the groups. This scale, engineered by the nurses in the neonatal intensive care unit may not be the best way to gauge parental satisfaction going forward.

### **Limitations**

Several limitations were identified in the design of the study. Due to time constraints of data collection and analysis, the intervention group enrollment was halted 3 weeks earlier than anticipated. Instead of enrolling patients throughout the entire month of September, enrollment was stopped after the first week. This gave way to a smaller sample size in the intervention group and possibly affected some of the results.

The intervention group was the first group of parents taught by the COPE for HOPE champion nurses. The COPE nurses were still learning the best approaches and becoming familiar with the content when the intervention group was enrolled. After months of teaching COPE sessions, the champion nurses would be expected to make a greater impact with parents as their teaching skills will improve and become more effective. This could be a limitation of the study and a greater effect in the variables could be noticed after the program has been implemented for a longer time frame.

Another limitation of the study could be the design of the parent satisfaction surveys. These surveys were designed by the nurses in the Baptist Lexington NICU as a tool to use for internal measure of parent satisfaction. In addition to the nurses being the designer of the survey, they are also performing the call to parents after discharge. Parents may not feel comfortable sharing negative feedback with nurses they know from the NICU stay. This could explain why both groups were almost 100% alike with no difference between the groups.

The design of the COPE teaching sessions in the Baptist ICU could also be a limitation of the study. The specially trained COPE nurses completed the teaching sessions and interventions with the parents during their normally scheduled days to work in the unit. Although the sessions with the parents were not designed to last longer than 10 to 15 minutes, this was done in addition to the nurses' normal responsibilities, so there may have been times when the nurse felt rushed to complete the COPE sessions due to other job responsibilities. This may have decreased the total benefit for parents in relation to stress, depression, and ultimately length of stay.

### **Recommendations for future studies**

Recommendations for future studies include additional approaches to parent empowerment as well as different ways to facilitate the COPE for HOPE program. In the NICU,

the providers and nurses are traditionally focused on the physiologic wellbeing of the patient. However, more research is indicating that the health of the parents is also important and could affect the outcomes of the NICU patient. Identifying a way to incorporate parent empowerment activities and teaching into the workflow of the NICU would be meaningful as most NICU's are charged with maintaining a certain productivity level; unfortunately, this program requires more time from the bedside nurse. Another recommendation would be to use a parent satisfaction tool that would represent a better picture of parental hospital satisfaction. In addition to a different tool, having different personnel complete the survey could also help with more accurate results.

Completing a study in the NICU after the COPE program has been implemented for a longer period of time would be a recommendation for a future study. A greater effect on the variables would be likely with nurses who are more comfortable with the program.

Designing a study that would track parental stress and depression throughout the first year of life would be another recommendation. Collecting information during the entire first year could give insight into more meaningful results of early parent empowerment in the NICU.

### **Conclusion**

Empowering and educating parents about their premature infant using the COPE for HOPE program appears to have decreased the parental stress of parents of premature infants in the neonatal intensive care unit, and more specifically their parental role. These results support the importance of family centered care and the parental role in the neonatal intensive care unit. Supporting parents and decreasing the barriers that are often felt by parents in the NICU remain an important problem that NICU personnel must overcome. The results of this study, in addition to other studies on this program substantiate the fact that parents in the NICU need support and

guidance from the staff. Parent empowerment programs should continue to be researched and designed in a way that coincides with the bedside nurses existing responsibilities.



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## Tables

<i>Inclusion/Exclusion Criteria</i>	
<b>Inclusion</b>	<b>Exclusion</b>
Less than 35 weeks gestation	Lethal congenital anomaly
English as preferred language as well as the ability to read and write English	
Born at Baptist Health Lexington	Parents who have had a previous child in the NICU
Parents greater 18 years old or greater	

**Table 1.** *Inclusion/Exclusion Criteria*

<i>Pre-Intervention Cohort</i>	
<b>Survey/Data Collected</b>	<b>Timeframe Completed</b>
PSS: NICU	Day of Life 3-5
EPDS	1-7 Days before discharge
Baptist Lexington Parent Satisfaction Survey	2-4 Weeks after discharge
Demographic Data and Length of Stay Data	Obtained during Hospitalization

**Table 2.** *Pre-Intervention Cohort*

<i>Intervention Cohort</i>	
<b>Survey/Data Collected/COPE Phase Completed</b>	<b>Timeframe Completed</b>
<i>Phase 1: Cope for Hope Program-Helping Your Premature Baby Grow and Develop</i>	Day of life 2-4
PSS: NICU	Day of life 3-5 and /or the day after Phase 1 Completed
<i>Phase 2: Cope for Hope Program-Helping Yourself and Your Baby: The Early NICU Days</i>	Day of Life 7-10
<i>Phase 3: Cope for Hope Program-Getting Ready to go Home Together</i>	1-7 Days before Discharge
EPDS	Complete before discharge and/or the day after Phase 3 is Complete
<i>Phase 4: Cope for Hope-Adjusting to Life at Home with Your Baby</i>	1-2 Weeks after Discharge
Parent Satisfaction Survey	2-4 Weeks after Discharge
Demographic Data and Length of Stay Data	During Hospitalization

**Table 3.** *Intervention Cohort*

Cohort	Gender	N	Gestational Age Mean
Pre-Intervention 29 Parent Sets	Male	14	33.28
	Female	15	
Intervention 20 Parent Sets	Male	5	31.89
	Female	15	

**Table 4.** *Group Characteristics*

PSS: NICU Subscale	Pre-Intervention	Intervention
Sights and Sounds	8.86	7.32
Infant Appearance	29.11	21.63
Parental Role	25.22	19.42
Total	63.07	48.37

**Table 5.** *PSS: NICU Statistics*



EPDS	N	Mean
Pre-Intervention	23	6.70
Intervention	16	4.13

**Table 6.** *EPDS Statistics*

Appendix A

**PARENTAL STRESS SCALE: NEONATAL INTENSIVE CARE UNIT**

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Copy of Tool  
Psychometrics and References  
Information for Researchers  
Permission Form

2015

Study Number \_\_\_\_\_

Date Completed \_\_\_\_\_

## PARENTAL STRESS SCALE: NEONATAL INTENSIVE CARE UNIT

We are interested in knowing more about the stresses experienced by parents when a premature is sick and hospitalized in an neonatal intensive care unit (NICU). We would like to know about your experience as a parent whose child is presently in the NICU.

This questionnaire lists various experiences other parents have reported as stressful when their baby was in the NICU. We would like you to indicate how stressful each item listed below has been for you. **By stressful, we mean that the experience has caused you to feel anxious, upset, or tense.** On the questionnaire, circle the single number that best expresses how stressful each experience has been for you. The numbers indicate the following levels of stress:

- 1 = Not at all stressful the experience did not cause you to feel upset, tense, or anxious
- 2 = A little stressful
- 3 = Moderately stressful
- 4 = Very stressful
- 5 = Extremely stressful

If you have not experienced an item, please circle NA "not applicable"

Now let's take an item for an example: **The bright lights in the NICU.**

If for example you feel that the bright lights in the neonatal intensive care unit were extremely stressful to you, you would circle the number 5 below:

NA 1 2 3 4 **5**

If you feel that the lights were not stressful at all, you would circle the number 1 below:

NA **1** 2 3 4 5

Below is a list of the various **SIGHTS AND SOUNDS** commonly experienced in an NICU. We are interested in knowing about your view of how stressful these **SIGHTS AND SOUNDS** are for you. Circle the number that best represents your level of stress. If you did not see or hear the item, circle the NA meaning "Not applicable."

- |    |  |              |
|----|--|--------------|
| 1. | The presence of monitors and equipment         | NA 1 2 3 4 5 |
| 2. | The constant noises of monitors and equipment  | NA 1 2 3 4 5 |
| 3. | The sudden noises of monitor alarms            | NA 1 2 3 4 5 |
| 4. | The other sick babies in the room              | NA 1 2 3 4 5 |
| 5. | The large number of people working in the unit | NA 1 2 3 4 5 |

Below is a list of items that might describe the way your **BABY LOOKS AND BEHAVES** while you are visiting in the NICU as well as some of the **TREATMENTS** that you have seen done to the baby. Not all babies have these experiences or look this way, so circle the NA, if you have not experienced or seen the listed item. If the item reflects something that you have experienced, then indicate how much the experience was stressful or upsetting to you by circling the appropriate number.

- |     |   |              |
|-----|---|--------------|
| 6.  | Tubes and equipment on or near my baby  | NA 1 2 3 4 5 |
| 7.  | Bruises, cuts or incisions on my baby   | NA 1 2 3 4 5 |
| 8.  | The unusual color of my baby<br>(for example looking pale or<br>yellow jaundiced) | NA 1 2 3 4 5 |
| 9.  | My baby's unusual or abnormal breathing<br>patterns                               | NA 1 2 3 4 5 |
| 10. | The small size of my baby   | NA 1 2 3 4 5 |
| 11. | The wrinkled appearance of my baby  | NA 1 2 3 4 5 |
| 12. | Having a machine (respirator)<br>breathe for my baby                              | NA 1 2 3 4 5 |
| 13. | Seeing needles and tubes<br>put in my baby  | NA 1 2 3 4 5 |
| 14. | My baby being fed by an intravenous<br>line or tube                               | NA 1 2 3 4 5 |
| 15. | When my baby seemed to be in pain   | NA 1 2 3 4 5 |
| 16. | When my baby looked sad   | NA 1 2 3 4 5 |
| 17. | The limp and weak appearance of<br>my baby  | NA 1 2 3 4 5 |
| 18. | Jerky or restless movements of my baby  | NA 1 2 3 4 5 |
| 19. | My baby not being able to cry like<br>other babies                                | NA 1 2 3 4 5 |

The last area we want to ask you about is how you feel about your own **RELATIONSHIP** with the baby and your **PARENTAL ROLE**. If you have experienced the following situations or feelings, indicate how stressful you have been by them by circling the appropriate number. Again, circle NA if you did not experience the item.

- |     |   |              |
|-----|---|--------------|
| 20. | Being separated from my baby  | NA 1 2 3 4 5 |
| 21. | Not feeding my baby myself  | NA 1 2 3 4 5 |
| 22. | Not being able to care for my baby myself (for example, diapering, bathing)     | NA 1 2 3 4 5 |
| 23. | Not being able to hold my baby when I want                                      | NA 1 2 3 4 5 |
| 24. | Feeling helpless and unable to protect my baby from pain and painful procedures | NA 1 2 3 4 5 |
| 25. | Feeling helpless about how to help my baby during this time                     | NA 1 2 3 4 5 |
| 26. | Not having time alone with my baby  | NA 1 2 3 4 5 |

Thank you for your help.

Feel free to write about other situations that you found stressful during the time that your baby was in the neonatal intensive care unit?

**c Margaret S. Miles, RN, PhD 1987, 2004, 2011**

## Appendix B

### Edinburgh Postnatal Depression Scale<sup>1</sup> (EPDS)

Name: \_\_\_\_\_ Address: \_\_\_\_\_

Your Date of Birth: \_\_\_\_\_

Baby's Date of Birth: \_\_\_\_\_ Phone: \_\_\_\_\_

As you are pregnant or have recently had a baby, we would like to know how you are feeling. Please check the answer that comes closest to how you have felt IN THE PAST 7 DAYS, not just how you feel today.

Here is an example, already completed.

I have felt happy:

- Yes, all the time
- Yes, most of the time This would mean: "I have felt happy most of the time" during the past week.
- No, not very often Please complete the other questions in the same way.
- No, not at all

In the past 7 days:

- |  |  |
|--|--|
| <p>1. I have been able to laugh and see the funny side of things</p> <ul style="list-style-type: none"><li><input type="checkbox"/> As much as I always could</li><li><input type="checkbox"/> Not quite so much now</li><li><input type="checkbox"/> Definitely not so much now</li><li><input type="checkbox"/> Not at all</li></ul> <p>2. I have looked forward with enjoyment to things</p> <ul style="list-style-type: none"><li><input type="checkbox"/> As much as I ever did</li><li><input type="checkbox"/> Rather less than I used to</li><li><input type="checkbox"/> Definitely less than I used to</li><li><input type="checkbox"/> Hardly at all</li></ul> <p>*3. I have blamed myself unnecessarily when things went wrong</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Yes, most of the time</li><li><input type="checkbox"/> Yes, some of the time</li><li><input type="checkbox"/> Not very often</li><li><input type="checkbox"/> No, never</li></ul> <p>4. I have been anxious or worried for no good reason</p> <ul style="list-style-type: none"><li><input type="checkbox"/> No, not at all</li><li><input type="checkbox"/> Hardly ever</li><li><input type="checkbox"/> Yes, sometimes</li><li><input type="checkbox"/> Yes, very often</li></ul> <p>*5. I have felt scared or panicky for no very good reason</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Yes, quite a lot</li><li><input type="checkbox"/> Yes, sometimes</li><li><input type="checkbox"/> No, not much</li><li><input type="checkbox"/> No, not at all</li></ul> | <p>*6. Things have been getting on top of me</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Yes, most of the time I haven't been able to cope at all</li><li><input type="checkbox"/> Yes, sometimes I haven't been coping as well as usual</li><li><input type="checkbox"/> No, most of the time I have coped quite well</li><li><input type="checkbox"/> No, I have been coping as well as ever</li></ul> <p>*7. I have been so unhappy that I have had difficulty sleeping</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Yes, most of the time</li><li><input type="checkbox"/> Yes, sometimes</li><li><input type="checkbox"/> Not very often</li><li><input type="checkbox"/> No, not at all</li></ul> <p>*8. I have felt sad or miserable</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Yes, most of the time</li><li><input type="checkbox"/> Yes, quite often</li><li><input type="checkbox"/> Not very often</li><li><input type="checkbox"/> No, not at all</li></ul> <p>*9. I have been so unhappy that I have been crying</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Yes, most of the time</li><li><input type="checkbox"/> Yes, quite often</li><li><input type="checkbox"/> Only occasionally</li><li><input type="checkbox"/> No, never</li></ul> <p>*10. The thought of harming myself has occurred to me</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Yes, quite often</li><li><input type="checkbox"/> Sometimes</li><li><input type="checkbox"/> Hardly ever</li><li><input type="checkbox"/> Never</li></ul> |
|--|--|

Administered/Reviewed by \_\_\_\_\_ Date \_\_\_\_\_

<sup>1</sup>Source: Cox, J.L., Holden, J.M., and Sagovsky, R. 1987. Detection of postnatal depression: Development of the 10-item Edinburgh Postnatal Depression Scale. *British Journal of Psychiatry* 150:782-786 .

<sup>2</sup>Source: K. L. Wisner, B. L. Parry, C. M. Piontek, Postpartum Depression N Engl J Med vol. 347, No 3, July 18, 2002, 194-199

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Appendix C

Parent Satisfaction Survey

Patient Name: \_\_\_\_\_ Boy \_\_\_\_\_ Girl \_\_\_\_\_

DOB \_\_\_\_\_ Gest Age \_\_\_\_\_

D/C Date \_\_\_\_\_ Home \_\_\_\_\_ Transfer \_\_\_\_\_ Foster care \_\_\_\_\_ Length of stay \_\_\_\_\_

Parent name \_\_\_\_\_ Mom's phone # \_\_\_\_\_

Follow-up call by \_\_\_\_\_ Date \_\_\_\_\_ Time \_\_\_\_\_

Overall, on a scale of 1-5, with 1 being the worst and 5 being the best, how satisfied were you with the overall quality of care and services provided by the BHL NICU?

1 2 3 4 5

Scale of 1-5, did you feel the NICU staff, including nurses, doctors, unit clerks, housekeepers, etc., were courteous and respectful throughout your hospital stay?

1 2 3 4 5

Scale of 1-5, did you feel like the nurses who took care of your baby were easy to talk to and willing to answer your questions?    1   2   3   4   5

Scale of 1-5, did you feel like the doctors who took care of your baby were easy to talk to and willing to answer your questions?    1   2   3   4   5

Scale of 1-5, did you feel our teaching was adequate to prepare you to care for your baby at home?  
1   2   3   4   5

We're always looking for ways to make things better for our families. Do you have any suggestions for how we could do this?