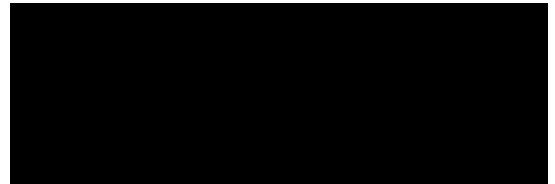


NICU MOMS: Examining Maternal Health  
Behaviors During the First Postpartum Year  
Among Mothers Delivering an Infant Spending a  
Week or longer in the Neonatal Intensive Care Unit

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## ABSTRACT

**Objective:** This study sought to investigate how the maternal experience of having an infant in the neonatal intensive care unit (NICU) for  $\geq 1$  week impacted maternal healthcare needs during her first postpartum year.

**Methods:** A web-based survey was pilot tested and launched via the NICU\_MOMS Twitter account. This survey was open from September 11, 2013- October 30, 2013.

**Results:** 221 mothers began the survey, with 131 completing it. A high score on the Modified Perinatal Post-Traumatic Stress Disorder Questionnaire was inversely associated with maternal health seeking behavior during her first postpartum year.

**Conclusion:** Mothers of babies in the NICU for  $\geq 1$  week should be screened using the MPTSD-PPQ tool to identify mothers having an elevated risk of PTSD.

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## **Background**

Each year in the United States, more than 390,000 infants are admitted to a Neonatal Intensive Care Unit (NICU).<sup>1 2</sup> Having a newborn admitted to the NICU can be stressful for mothers, who must recover from childbirth while caring for a critically ill newborn. Support for these mothers might improve the health of the mother and the baby, but the needs of NICU moms are not well understood. To address this gap in the literature, we sought to assess the postpartum psychosocial and health care needs of mothers whose infants spent a week or longer in the NICU.

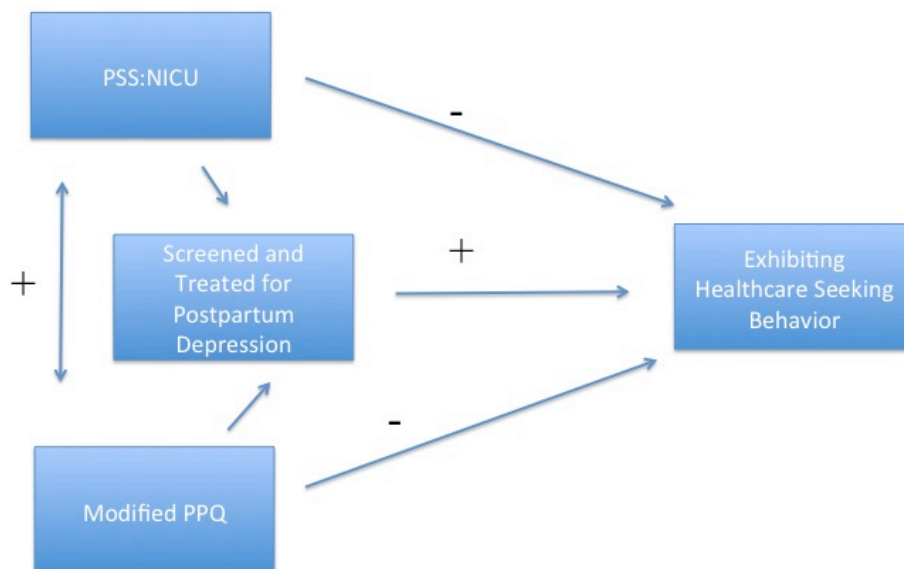
This research paper examines maternal stressors and needs while having a baby (or babies) in the NICU and quantifies unmet maternal health needs during the first year after childbirth. For these mothers, the postpartum period poses unique challenges for accessing the healthcare and support they need in addition to caring for their medically fragile infant. The maternal health seeking behaviors that will be examined in this paper include having a medical provider, being satisfied with her current form of contraception, being screened for postpartum depression and treated (if indicated), and delaying medical care for herself during her NICU baby's first year of life.

Given the wide range of influences that impact maternal health while the having a new baby in the NICU and throughout baby's first year of life, this paper examines two specific aspects of maternal care and support. This study seeks to answer the following questions: 1) Does a mother's stress related to her infant's birth and the experience of having an infant in the NICU, indexed by the Modified Perinatal PTSD (MPPTSD) scale and the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU), impact her healthcare seeking activities during her child's first year of life?, 2) Is there a relationship between postpartum depression screening

and perinatal stress? and 3) What additional resources do NICU mothers indicate would have been helpful while having a baby was in the NICU and throughout the child's first year of life?

A conceptual model (Figure 1) was created to describe the relationships between stressors and maternal health seeking behaviors during the 12 months following the birth of a woman's most recent NICU baby. We hypothesized maternal stress associated with the infant's birth is associated with stress experienced in the NICU. We further hypothesized that that increased maternal stress, indexed by PSS: NICU or MPPTSD score, is associated with reduced health seeking behaviors. We hypothesized that mothers who were screened for depression and treated (if indicated) would be more likely to exhibit healthcare seeking behaviors in the first postpartum year.

**Figure 1: Conceptual model of the relationship between maternal stress, depression screening and treatment, and healthcare-seeking behavior**



## **Methods**

A literature review was conducted using a PubMed search of “neonatal intensive care unit maternal health,” which yielded 780 results. These results were narrowed, excluding articles that were not in English or did not relate to maternal health topics among women delivering a child that was subsequently admitted to the NICU, leaving 47 abstracts for additional review. Of these articles, additional articles were excluded that concerned topics related to newborn and infant health outcomes. Studies relevant to the NICU experience and the first year of the child’s life will be described below.

While there has been extensive research regarding maternal depression among new mothers, some of which is specific to mothers in the NICU, much of this research is limited to scores on screening instruments for depression. There is limited research on strategies for and effectiveness of postpartum depression screening and follow-up support. We sought to quantify prevalence of screening and treatment, and we measured maternal stress using the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU) and the Modified Perinatal PTSD (MPPTSD) scale. We selected these instruments so as to identify specific points of stress that mothers experience while having a baby in the NICU. Additionally, maternal preferences for support during the NICU stay are unknown. The research presented in this paper will attempt to address this gap.

### **Neonatal Intensive Care Unit**

The neonatal intensive care unit can be a stressful environment for new mothers. Newborn babies are admitted to the NICU for a variety of reasons. The March of Dimes and the National Perinatal Information Center/Quality Analytic Services (NPIC/QAS) reports that 14.4%

of 183,030 infants born in the study period were admitted to a special care nursery and admitted babies had an average stay of 13.2 days.<sup>4</sup>

Mothers having infants in the NICU are at an increased risk of developing acute stress disorder, defined as a “form of traumatic stress that is experienced in the first weeks after a traumatic event, [which] is considered to be a precursor to PTSD”.<sup>5</sup>

The stress associated with the being in the NICU does not end upon discharge. In a study of mothers 6 months after their infants were discharged from the NICU, many continued to report painful memories associated with the NICU.<sup>6</sup> Mothers recall the stress experienced in the NICU years later. Three years later, 94% of mothers recalled the stress associated with parenting a child in the NICU and the pain associated with being separated from the baby.<sup>7</sup> Mothers also experienced frustration with not being able to visit the baby due to transportation or financial reasons.<sup>7</sup>

## **Delivery Complications**

Childbirth is unpredictable. In 2011 in the United States, 11.2% of all births were preterm, defined as delivery occurred before 37 completed weeks of gestation. Additionally, 32.8% of all births were delivered by cesarean section, a major surgery.<sup>2</sup> Childbirth, vaginal or by cesarean section can be painful to the mother; causing pain that interferes with everyday activities months after birth.<sup>3</sup> Listening to Mothers III, a Report of the Third National U.S. Survey of Women’s Childbearing Experiences, published May 2013, found that 18% of deliveries resulted in an NICU admission and 6% of all deliveries resulted in NICU admissions lasting 6 days or longer.<sup>3</sup> The NICU admission rates varied among delivery method; 28% of admissions were from mothers that had a primary (first) caesarean, 16% of mothers that had a

vaginal birth after caesarean, 15% of mothers that had repeat cesarean and 16% of mothers who had a vaginal birth.<sup>3</sup> Of mothers having a caesarean, 33% of the infants receiving a NICU admission spent 6 or more days in the NICU.<sup>3</sup> Among women having a cesarean, maternal health conditions accounted for 11% (N= 368) of the primary cesareans and 13% (n=376) of repeat cesareans. Thus 43% of mothers of NICU infants were recovering from major surgery while their newborn was in an intensive care unit.

### **First year of caring for a NICU baby**

Caring for a medically fragile infant in the first year of life can be challenging for new mothers and the need for maternal healthcare and support does not end when the mother returns home. Returning home can bring increased anxiety and stress as the mother becomes the primary caretaker of her baby, who might require additional care.

Postpartum depression is common among all new mothers; studies suggested the rates are between 10-15% for all women.<sup>9</sup> The rate can be as high as 38% among mothers with chronic stressors, including infant difficulty and not enough money to meet basic needs, and those with poor social support.<sup>10</sup> Studies suggest depression symptoms are more prevalent among NICU mothers, with rates ranging from 28%-70%.<sup>11,12</sup> This results in substantial morbidity for mothers, and can also impact maternal and child health. Research suggests depressed mothers are less likely to seek medical care or support for their own health.<sup>13</sup> Studies also indicated depressed mothers are more likely to visit the emergency room for an issue related to their infants' health and less likely to utilize primary, preventative healthcare visits.<sup>13,14</sup>

Postpartum depression among NICU mothers is not limited to the immediate postpartum period. Stressors associated with caring for a medically fragile infant, especially rehospitalization



during the infant's first year of life, can contribute to mothers' continued struggle with depression.<sup>11</sup> Miles et al. report that 63% of NICU mothers reported depression symptoms at the time of the discharge from the NICU.<sup>11</sup> In follow-up surveys conducted 13 months after discharge and 22 after discharge, 21% of these mothers still scored 16 or higher on the Center for Epidemiologic Studies-Depression Scale.<sup>11</sup>

Maternal depression can impact the health of the mother and the child. Concerning maternal health, depression among first-time mothers places these women at higher risk for a rapid repeat pregnancy.<sup>15</sup> Data suggest that mothers with moderate to severe depression are 7.24 (95% CI: 2.18-24.04) times as likely to become pregnant within six months of delivering her first child. The wide confidence interval reflects the small N=12 of all mothers in the study (N= 279) who became pregnant within 6 months of delivery.<sup>15</sup> A shortened interval to next pregnancy is particularly concerning among mothers of medically fragile infants, because short interpregnancy interval is associated with higher risks of preterm birth, low birth weight and small for gestational age.<sup>16</sup>

Smoking can also be linked to postpartum depression, as mothers with depression are less able to discontinue or cut down on tobacco use. Among women who smoke prior to becoming pregnant and quit during pregnancy, as many as 85% resume smoking in 2-8 weeks following the delivery of her baby.<sup>17</sup> Mothers cite that anxiety, depression and a need for rest/relaxation among the reasons they resume smoking.<sup>18</sup> Maternal smoking has been linked to reproductive complications, menstrual dysfunction in addition to lung, bladder and cervical cancer.<sup>19</sup> Additionally, tobacco exposure among infants is linked to sudden infant death syndrome, ear infections, respiratory illness, asthma and deficits in cognitive and behavioral performances.<sup>19</sup>

Mothers that resume smoking are more likely to formula feed or to wean their infants at a younger age. <sup>20,21</sup>

### **Interventions for NICU parents**

There is little research on postpartum education for NICU parents. The Cochrane Review by Gagnon and Bryanton examined studies on infant sleeping, infant behavior, general post-birth health, infant safety and involving fathers among the general population. <sup>22</sup> Gagnon and Bryanton suggest that the benefits of postpartum parental educational classes for parents of healthy children are unclear. <sup>22</sup> While there are a number of programs seeking to address the maternal healthcare needs among NICU moms, there are no guidelines or standardized interventions to assess maternal needs and match those needs to support programs. This study seeks to address this gap in the literature by asking NICU mothers what support services or educational classes might have been helpful during the NICU stay and throughout the NICU infant's first year of life.

### **Survey Components**

An electronic survey (Appendix A) for this project, "NICU MOMS" was modified from a paper survey used in a research project, Postpartum Wellbeing and Health Care Needs of NICU Mothers, piloted by researchers at the University of North Carolina at Chapel Hill Department of Obstetrics and Gynecology Division of Maternal Fetal Medicine. The Postpartum Wellbeing study was conducted to identify unmet needs among mothers of medically fragile infants. These survey results are being used to inform development of new services for mothers of infants who spent time in the North Carolina Children's Hospital Neonatal Critical Care Unit. In the current

project, we sought to extend this pilot work to a broader audience through an online survey of NICU mothers. The survey was modified with guidance from staff at The Howard W. Odum Institute for Research in Social Science, located at the University of North Carolina at Chapel Hill.

The survey was designed to gather a wide range of information from NICU mothers regarding their pregnancy and postpartum period. Basic demographic information was captured first in the survey (age, socioeconomic status, education, number of adults and children in the household, insurance coverage) in order to obtain this basic information in the event the participant did not complete the survey. The following questions inquired about pregnancy history and previous NICU experiences with children admitted there for care. Mothers were asked general questions about each NICU experience, in the event that she had more than one pregnancy result with a baby warranting a NICU admission.

More detailed questions about the most recent NICU baby who spent a week or more in the NICU were asked to capitalize upon accuracy of recall for the mother. The survey includes two validated instruments for measuring perinatal stress, the Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU) and the Modified Perinatal Post-Traumatic Stress Disorder (PTSD) Questionnaire (PPQ). We then asked about healthcare seeking behavior of the mother during her child's first year of life, breastfeeding and breastfeeding support, contraception usage, and if specific resources would have been beneficial to the mother. Regarding postpartum depression, the survey asks

- 1) Were you screened for postpartum depression? (Yes/No)
- 2) If yes, were you diagnosed with postpartum depression? (Yes/No)
- 3) What help did you receive for your postpartum depression?
  - ☐ Therapy
  - ☐ Prescription Medication
  - ☐ Support Group- In person

- ☐ Support Group- Online
- ☐ None
- ☐ Other (Fill in)

Survey questions were organized to follow the timeline of the maternal NICU experience, followed by questions about the mother's experience during her baby's first year of life. See Appendix A for the specific survey order and questions.

The Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU) was included in the survey following specific questions about why the baby was admitted to the NICU (see Appendix B). Developed by Dr. Margaret Miles, RN, PhD, this scale assesses the parental perception of stress while having an infant in the NICU, as the NICU environment can be a major contributor to parental stress. The PSS:NICU accounts for the environmental factors in the NICU as well as the intrapersonal interactions that take place in the NICU.<sup>23</sup> This tool has good construct validity, indicating that the PSS:NICU is a valid tool in measuring the stressors felt by NICU parents while having a child in the NICU.<sup>5</sup>

The PSS:NICU is comprised of three parts. Part 1 includes 5 questions related to how the baby looks and behaves and the treatments that the baby receives while in the NICU. Part 2 includes 11 questions concerning the sights and sounds of the NICU environment, including the noises of machines and the larger number of people around. Part 3 includes 11 questions that address stressors related to the parental role alteration. These questions include not being able to physically be with and care for the baby as well as not being able to protect the baby from pain and painful procedures.<sup>23</sup> Prior research suggests that the changes in the parental role cause parents the most stress while being in the NICU. Studies indicate that parents experienced the most stress from feelings of helplessness from not being able to protect or help their child.<sup>24</sup>

In addition to the PSS: NICU, mothers completed the Modified Perinatal Post-Traumatic Stress Disorder (PTSD) Questionnaire (PPQ). This instrument assesses post-traumatic symptoms related childbirth including question related to feelings of guilt. Participants ranked frequency of symptoms on a Likert scale of ‘not at all,’ ‘once or twice,’ ‘sometimes,’ ‘often, but less than 1 month’ and ‘often, for more than a month.’<sup>25</sup> Past research suggests that severity of neonatal complications is the strongest predictor of higher PPQ scores. Data from Callahan et. al suggest that mothers who score 19 or higher on this instrument are nearly twice as likely to benefit from referral to mental health services.<sup>25</sup>

### **Inclusion criteria for participation**

We included women in our study who were:

- 1) at least 18 years of age,
- 2) comfortable reading English and
- 3) the birthmother of a child that spent at least 6 days in a NICU within the last five years.

### **Pilot Survey**

The online survey was pilot tested among members of the North Carolina Children’s Hospital Family Advisory Board (FAB), who advise the Neonatal Critical Care Center at the North Carolina Children’s Hospital in Chapel Hill, North Carolina, and among members of the Duke Children’s Hospital FAB, which advises the Duke Intensive Care Nursery at Duke Children’s Hospital and Health Center in Durham, North Carolina

### **Survey**

The online survey was implemented using Qualtrics 2013. Qualtrics was chosen because it allows for skip patterns and looping patterns based on the mother's number of pregnancies resulting in a NICU admission babies and if any deliveries included multiples. Given the wide range of experiences among NICU mothers, Qualtrics allowed each survey participant to only answer questions that would be pertinent to her pregnancies, births, and the first year postpartum for her most recent NICU birth.

The survey link for the NICU MOMS study was placed on the UNC Department of Obstetrics & Gynecology Research page, under "Ongoing Studies," along with a brief description of the NICU MOMS project. This webpage can be found at this URL: <https://www.med.unc.edu/obgyn/research/ongoing/nicu-moms>. The survey was given again to the FAB at UNC and Duke were given the survey again and encouraged to retake the survey. The survey was promoted on Twitter from a "NICU MOMS" account.

Using Twitter, researchers began following other medical organizations, hospitals, healthcare professionals, and premature infant groups that were actively posting messages. Many of these account holders responded by following the NICU MOMS account. Researchers also tweeted messages "at" these groups asking to "Pls RT" (please retweet). The messages on Twitter linked to the study description on the UNC Department of Obstetrics & Gynecology Research page. It was also promoted on Facebook from a "NICU MOMs" Facebook page; this also linked to the NICU MOMS study description on the UNC webpage. These links were directed to the NICU MOMS webpage hosted by UNC in order to assure research participants that this was a legitimate research study sponsored by an accredited institution. By allowing potential participants to read the inclusion criteria, we sought to reduce the number of individuals

who accessed the survey, but did not meet the survey qualifications. The survey results for this paper were collected beginning on September 11, 2013 and the ending on October 30, 2013.

The data was analyzed using SAS 9.3 (Cary, NC). The results examine the relationship between maternal age, socio-economic status, education, gestational age, infant birthweight, length of NICU stay and her total PSS:NICU score and MPTSD-PPQ scores. We examined the total PSS:NICU score as well as three subscales, Look and Behaves, Sights and Sounds, Parental Role, to see if there were trends among these three different types of stressors. The relationship between the total PSS:NICU score and MPTSD-PPQ was score was examined looking at the mother's health seeking behaviors during her infant's first year of life. For this paper, we define the outcome, exhibiting healthcare seeking behavior, as a composite of four questions, with each "yes" counting for 1 point.

- 1) Were you screened for depression (and treated if indicated) (Yes, No)
- 2) Did delay medical care for yourself (Yes, No)
- 3) Happy with form of birth control (Yes, No)
- 4) Has a healthcare provider (Yes, No)

We dichotomized health seeking behavior scores into "high" or "low" health seeking behavior, defined as having a score of 4 or less than 4. The survey also included open-ended questions regarding what mothers found helpful during their NICU experience and what could have been improved. We reviewed these qualitative responses for common themes.

## **Results**

### ***Pilot Survey***

The results and comments from the pilot survey encouraged researchers to extend the survey to a wider audience. While the survey covers many areas of the NICU experience and the

mother's first year postpartum, these pilot survey comments helped researchers to focus this paper on the mothers' stated gaps of care and the mothers' feedback on specific programs and support services that would have been helpful during their child's first year of life.

The qualitative feedback of the pilot study provided responses including "the staff was amazing at making me realize this was not my fault" and "I felt very included in my child's plan of care". Regarding what could have been improved her time in the NICU, another mother responded:

"I would have given anything for a place to rest while visiting my child. She arrived via emergency cesarean (sp) and so I was quite sore and very tired, both emotionally and physically, after her birth. However, this fatigue never kept me from spending as much as 15-18 hours a day with my child. We lived 45 minutes away at the time, so I didn't want to drive back home for a nap to just come back later. I would have appreciated a comfy chair, or a place to nap, for even just an hour a day somewhere in the NICU so I could still be close by my child. Also, having a professional counselor come by to talk to me while at the NICU bedside would have been very appreciated. Maybe had I had someone identify my PTSD and Postpartum Depression then, I could have acted sooner and gotten well sooner."

## **Survey Results**

There were 221 women that accessed this survey as of October 30, 2013. Of these women, 131 completed the survey, for a 59% completion rate. Participants dropped out of the survey at various time points, so the sample size for responses to each question varies. 91.02% of mothers taking this survey spent time in a NICU in the United States, 3% in Canada, 3.5% in the United Kingdom and 0.05% in each of the following: Australia, Belgium, Egypt and the United Arab Emirates. The median age among 194 participants was 33 years, ranging from 18-47 years of age.



Prior to delivery, 58% (95/186) of mothers were hospitalized during her most recent pregnancy that resulted in a NICU baby. Of these mothers, the average number of nights in the hospital was 8.21, with the range being 1-56 nights. At some point while having a baby in the NICU, 89% (148/166) of mothers stayed at their own home, 19% (31/166) stayed in a single family room in the NICU, 13% (22/166) stayed at a boarding room at the hospital.

Table 1 shows maternal characteristic, demographics and pregnancy information in relationship to the her total PSS:NICU score and her Modified Perinatal Post-Traumatic Stress Disorder Questionnaire score (MPTSD:PPQ) . The PSS:NICU score was divided above and below the median score of 24. The Modified Perinatal Post-Traumatic Stress Disorder (PTSD) Questionnaire (PPQ) was divided between high scores, defined as being greater and or equal to 19, and not high scores, less than 19. Mothers 35 or older reported higher scores on the PSS:NICU than mothers of other ages. Regarding PSS:NICU scores, 26.6% of Mothers completing a Masters degree as the highest level of education scored above the mean (higher than 24, while 21.3 scored below the mean (24 or below). More mothers completing high school, Masters Degree and Doctoral or Professional Degree scored 19 or higher on the Modified PTSD-PPQ (deemed at risk) than mothers who were not at risk. Infant birth weight and infant length of stay in the NICU did correspond to higher MPTSD-PPQ scores.

Data from Table 2 concerning the PSS:NICU scores suggest that “Baby looks and Behaves/Treatment Done to Baby” were more stressful for mothers with babies that were born at earlier gestational ages, had longer NICU lengths of stay, and were lower birth weight. Sights and sounds and parental role subscores did not appear to vary with infant or parental characteristics.

Among the 161 women who reported on all four health-seeking behaviors (Table 3), 43.23% (N=68) of women in this study did exhibit healthcare seeking behaviors in each of the four categories: 1 ) having a health care provider, 2) not delaying personal medical care/treatment and 3) being satisfied with current form of contraception and 4) screened and treated (if indicated) for depression. From Table 3, 34.7% of women exhibited 3 health seeking behaviors, 18.63% exhibited 2 health seeking behaviors, and 4.35% exhibited 1 health seeking behavior.

Women with an elevated MPTSD:PPQ score, 19 or higher, were significantly less likely to report all four health seeking behaviors during the first postpartum year than women without an elevated MPTSD:PPQ score, OR 0.34 (95% CI 0.15 - 0.72) (Table 4). Highest education level, days infant spent in the NICU and maternal age were not significantly associated with health seeking behavior.

Figure 1 suggests there was no correlation in this population between PPS:NICU scores and MPTSD:PPQ scores. This data suggests that the recall of stress experience in the NICU is not correlated with stress related to childbirth.

Mothers were asked a number of free response questions in the survey. From mothers who delayed medical care, one mother explained “I had four kids four and under two with serious special needs, unless I was dying I wasn't going to a doctor” and another mother responded “my son needed so much medical care I didnt have a chance to worry about myself”.

Displayed in Figure 2, the majority of mothers taking this survey lacked childcare for older children (83.8 %) and a support person coming to her home (86.16). Answering what would have been helpful while having a baby in the NICU, Figure 3, 70.59% stated it would be

very helpful to have childcare for my older children and 62.07% stated it would be very helpful to have parking vouchers.

Regarding the helpfulness of potential NICU programs, Figure 5, 92.91% said it would be somewhat helpful or very helpful to have an online forum to interact with other NICU parents. 91.17% stated it would be very helpful or somewhat helpful to have a counseling session to help process my birth experience. 61.15% of mothers stated it would be very helpful to have a parent-buddy program for support.

Answering the open ended questions, mothers responded about what was helpful during the NICU stay. Mothers commented on the support programs:

“Our hospital has a Parent-to-Parent program which was AMAZING...we are still friends to this day. Post-NICU support is amazing, as that is when many emotions start to hit.”

“I was paired with a family who had had a baby born at 23 weeks 2 years earlier. I almost did not take my Nicu up on the offer to have a parent to parent volunteer follow me through the Nicu experience, because I figured there were no other parents who had babies as small as my baby had been. It was really really touching to see their 2 year old and know that my son could live. we also had a March of Dimes Nicu Family Support Program at the hospital, and that was hugely helpful, especially the sibling lunches and dinners, for helping my other two children understand what their brother was going through and why he had to stay at the hospital for 5 months. lunches with lactation consultants were helpful as I tried to express milk for my son, and the private room was so nice for me. My NICU had two types of rooms private rooms and the traditional nurseries. We got put in a private room, and I was so glad. I was able to meet with other parents on my own time and for my own supportgroup whie stilll having private time with my son.”

Responding to what would have been helpful while being the NICU, a number of mother commented on a support group:

“I would have loved a parent support group. Once we met some other families on our own we found it to be very encouraging and helpful. We made some life long friends in the NICU.”

“ More parent support - in all forms. Patient/Family centered care would have helped. Private rooms, the ability to sleep-in with baby, sibling visitation, more information on PPD and PTSD so parents can know what to expect,”

“Being prepped before the first time walking into the NICU on procedures, what I was going to see, a list of resources that I could use to help me get through our stay...instead of having to find them completely on my own.”

“More peer support. I had support from other moms but all with later term babies, and they were currently going through it, a buddy would have been great for me. More access to mental health care, I was diagnosed with severe PTSD at six months post natal and I think this could be somewhat mitigated or prevented by better care during the NICU period Our unit was terrible at breastfeeding support. We were in a lower level NICU and they'd never supported a breastfeeding mom of an IUGR 27 weeker and it showed. I now know where to get help and support but too late now!”

## **Discussion**

Data from this project suggests that there is a significant inverse association between maternal healthcare seeking behaviors and having a traumatic birth experience among mothers having an infant in the NICU for a week or longer. Results also suggest that mothers would like support services, such as support groups or a parent-buddy system, to help navigate the NICU stay.

For future survey studies, we would recommend modifying several questions. Regarding contraception, it is important to ask if the woman is currently pregnant. On questions related to where the mother stayed while her baby was in the NICU, there needs to be a response option that the mother was also a patient in the hospital (or at another hospital). It would be helpful to allow the mother to state all of the places she stayed, and for how many nights (approximately) she stayed at each place.

## **Limitations**

Our findings must be interpreted in the context of the study design. The sample size lacked diversity among race/ethnicity of mothers, which limits the generalizability of the study findings. This survey was only available to mothers with internet access. Additionally, the survey was largely promoted using Twitter and Facebook, which also limited the respondent population to mothers using social media and following NICU related topics. The large percentage of NICU moms stating they would be interested in an online support group might be a result of recruiting mothers who were already using web-based resources for NICU moms., The length of the survey resulted in substantial drop-off among the respondents. Among the mothers who did not complete the survey, it is not known what caused these women to stop part way through the survey. Another limitation from this survey is that all of the data in the survey was self-reported and it was not verified by medical records. However, the survey's internet-based design allowed us to reach women in 5 countries and 12 states in the United States, take into consideration multiple NICU pregnancies, and receive detailed feedback from 62.3% (N= 137) of mothers who answered "please tell us what was positive about your NICU experience" and 59.7% (N= 132) of participants answered the open ended question "Please tell us about what could have improved your NICU experience".

### **Policy implications/recommendations and significance for Maternal Child Health**

The data from this research project is beneficial for the field of Maternal and Child Health because it addresses a gap in the literature regarding the relationship between having a NICU baby and maternal health. Given that a high Modified PTSD-PPQ score was significantly associated with reduced maternal healthcare seeking behavior the first postpartum year, a recommendation would be to use this instrument to screen all NICU MOMS who have a baby in

the hospital more than 6 days. Mothers with elevated scores could be referred to additional support, provider screening and resources.

Comments from participants suggest that they would like more peer support from former NICU moms while in the NICU. The data also suggests that mothers would benefit from an orientation to the NICU environment upon the admission of the NICU baby (or maternal discharge from the hospital).

In preparing for this study, we identified a lack of national data on admission to the NICU. The new U.S. birth certificate includes NICU admission, but has not been implemented nationally. For 2011 (the most recent comprehensive analysis of United States birth data), 36 states and the District of Columbia had implemented the use of the revised birth certificate.<sup>2</sup> It is important for this information to be collected in order for researchers to have a comprehensive understanding regarding the national utilization of NICUs.

During recruitment for this research project, researchers were contacted by the National Perinatal Association to assist in the development of “Program Standards for Mental Health Services for Parents of Infants Admitted to the Neonatal Intensive Care Unit” over the next few years. The findings from this project will be shared with stakeholders in order to address this gap in patient care, as there are no clear guidelines or standards of care for mental health support, services or screenings among mothers in the NICU.<sup>26</sup>

## **Conclusion**

Further research is needed to better understand the impact a traumatic birth experience has on mother of babies admitted to the NICU. Mothers of NICU babies should be screened using the Modified Perinatal Post-Traumatic Stress Disorder (PTSD) Questionnaire (PPQ) in

order to identify mothers who might need additional support services. Research is also needed to understand how all NICU mothers can be supported while caring for their child in the NICU and throughout the first year postpartum.

### **Works Cited:**

- (1) Berns SD, editor. Toward Improving the Outcome of Pregnancy III: Enhancing Perinatal Health Through Quality, Safety and Performance Initiatives. Reissued edition. White Plains, NY: March of Dimes Foundation; 2011.
- (2) Martin JA, Hamilton BE, Ventura SJ, et al. Births: Final Data for 2011. National Vital Statistics Reports; vol 62, no 1. Hyattsville, MD: National Center for Health Statistics. 2013.
- (3) Special Care Nursery Admissions. March of Dimes and National Perinatal Information Center/Quality Analytic Services. 2011.
- (4) Shaw RJ, Deblois T, Ikuta L, Ginzburg K, Fleisher B, Koopman C. Acute Stress Disorder Among Parents of Infants in the Neonatal Intensive Care Nursery. *Psychosomatics* 2006 0;47(3):206-212.
- (5) Affleck G, Tennen H, Rowe J, Higgins P. Mothers' remembrances of newborn intensive care: a predictive study. *J.Pediatr.Psychol.* 1990 Feb;15(1):67-81.
- (6) Wereszczak J, Miles MS, Holditch-Davis D. Maternal recall of the neonatal intensive care unit. *Neonatal Netw.* 1997 Jun;16(4):33-40.
- (7) Declercq ER, Sakala C, Corry MP, Applebaum S, Herrlich A. Listening to Mothers III: Pregnancy and Birth. May 2013.
- (8) O'Hara M.W., Swain A.M.: Rates and risk of postpartum depression—a meta-analysis. *Int Rev Psychiatry* 1996; 8: 37-56.
- (9) Séguin L, Potvin L, St-Denis M, Loiseleur J. Depressive Symptoms in the Late Postpartum Among Low Socioeconomic Status Women. *Birth* 1999;26(3):157-163.
- (10) Miles MS, Holditch-Davis D, Schwartz TA, Scher M. Depressive symptoms in mothers of prematurely born infants. *J.Dev.Behav.Pediatr.* 2007 Feb;28(1):36-44.
- (11) Miles MS, Holditch-Davis D, Burchinal P, Nelson D. Distress and growth outcomes in mothers of medically fragile infants. *Nurs.Res.* 1999 May-Jun;48(3):129-140.

- (12) Murray L, Woolgar M, Murray J, Cooper P. Self-exclusion from health care in women at high risk for postpartum depression. *J.Public Health Med.* 2003 Jun;25(2):131-137.
- (13) Minkovitz CS, Strobino D, Scharfstein D, Hou W, Miller T, Mistry KB, et al. Maternal depressive symptoms and children's receipt of health care in the first 3 years of life. *Pediatrics* 2005 Feb;115(2):306-314.
- (14) Patchen L, Lanzi RG. Maternal depression and rapid subsequent pregnancy among first time mothers. *MCN Am.J.Matern.Child Nurs.* 2013 Jul-Aug;38(4):215-220.
- (15) Conde-Agudelo A, Rosas-Bermudez A, Kafury-Goeta AC. Birth spacing and risk of adverse perinatal outcomes: a meta-analysis. *JAMA* 2006 Apr 19;295(15):1809-1823.
- (16) Phillips RM, Merritt TA, Goldstein MR, Deming DD, Slater LE, Angeles DM. Prevention of postpartum smoking relapse in mothers of infants in the neonatal intensive care unit. *J.Perinatol.* 2012 May;32(5):374-380.
- (17) Suplee PD. The Importance of Providing Smoking Relapse Counseling During the Postpartum Hospitalization. *Journal of Obstetric, Gynecologic, & Neonatal Nursing* 2005;34(6):703-712.
- (18) Levine MD, Marcus MD, Kalarchian MA, Cheng Y. Strategies to Avoid Returning to Smoking (STARTS): A Randomized Controlled Trial of Postpartum Smoking Relapse Prevention Interventions. *Contemp.Clin.Trials* 2013 Oct 17.
- (19) Liu J, Rosenberg K, Sandoval A. Breastfeeding duration and perinatal cigarette smoking in a population-based cohort. *Am J Public Health* 2006;96(2):309-31.
- (20) Horta B, Kramer M, Platt R. Maternal smoking and the risk of early weaning: a meta-analysis. *Am J Public Health* 2001;91(2):304-307.
- (21) Gagnon AJ, Bryanton J. Postnatal parental education for optimizing infant general health and parent-infant relationships. *Cochrane Database Syst.Rev.* 2009 Jan 21;(1):CD004068. doi(1):CD004068.
- (22) Miles MS, Funk SG, Carlson J. Parental Stressor Scale: neonatal intensive care unit. *Nurs.Res.* 1993 May-Jun;42(3):148-152.
- (23) Miles MS, Funk SG, Kasper MA. The neonatal intensive care unit environment: sources of stress for parents. *AACN Clin.Issues Crit.Care Nurs.* 1991 May;2(2):346-354.
- (24) Callahan JL, Borja SE, Hynan MT. Modification of the Perinatal PTSD Questionnaire to enhance clinical utility. *J.Perinatol.* 2006 Sep;26(9):533-539.



(25) The National Perinatal Association. Proposal for a Multidisciplinary Workgroup to Develop Program Standards for Mental Health Services for Parents of Infants Admitted to the Neonatal Intensive Care Units. 2013.

**Table 1: Descriptives by PSS Score and PTSD- PPQ Score**

	PSS NICU (sum of all)						Modified Perinatal Post-Traumatic Stress Disorder (PTSD) Questionnaire (PPQ)						All	
	Missing		<= 24 (median)		> 24		Missing		<19		>=19			
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Maternal age														
18 to <26	1	1.6	4	5.0	3	3.8	0	0.0	2	4.1	6	5.4	8	3.6
26 to < 35	16	25.8	46	57.5	45	57.0	15	25.0	25	51.0	67	59.8	107	48.4
35+	18	29.0	30	37.5	31	39.2	18	30.0	22	44.9	39	34.8	79	35.7
Missing	27	43.5	0	0.0	0	0.0	27	45.0	0	0.0	0	0.0	27	12.2
Race/Ethnicity														
White	30	48.4	78	97.5	74	93.7	29	48.3	45	91.8	108	96.4	182	82.4
Asian	1	1.6	1	1.3	0	0.0	1	1.7	0	0.0	1	0.9	2	0.9
Black or African American	1	1.6	1	1.3	1	1.3	0	0.0	2	4.1	1	0.9	3	1.4
Other	1	1.6	0	0.0	2	2.5	1	1.7	2	4.1	0	0.0	3	1.4
White, American Indian or Alaska Native	0	0.0	0	0.0	1	1.3	0	0.0	0	0.0	1	0.9	1	0.5
White, other	1	1.6	0	0.0	0	0.0	1	1.7	0	0.0	0	0.0	1	0.5
Black or African American, White, American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander	0	0.0	0	0.0	1	1.3	0	0.0	0	0.0	1	0.9	1	0.5
Missing	28	45.2	0	0.0	0	0.0	28	46.7	0	0.0	0	0.0	28	12.7
What is the highest level of education you have completed?														
missing	33	53.2	0	0.0	0	0.0	33	55.0	0	0.0	0	0.0	33	14.9
High school	3	4.8	14	17.5	14	17.7	3	5.0	7	14.3	21	18.8	31	14.0
Associates degree (AA, AS, etc)	2	3.2	7	8.8	6	7.6	3	5.0	4	8.2	8	7.1	15	6.8
Baccalaureate degree (BA, BS, BSBA, etc)	16	25.8	37	46.3	35	44.3	14	23.3	25	51.0	49	43.8	88	39.8
Masters degree (MA, MS, etc)	6	9.7	17	21.3	21	26.6	5	8.3	11	22.4	28	25.0	44	19.9
Doctoral or Professional degree (PhD, MD, JD, DDS, etc)	2	3.2	5	6.3	3	3.8	2	3.3	2	4.1	6	5.4	10	4.5
What was your total household income, before taxes, in 2012?														
missing	33	53.2	1	1.3	0	0.0	33	55.0	0	0.0	1	0.9	34	15.4

	PSS NICU (sum of all)						Modified Perinatal Post-Traumatic Stress Disorder (PTSD) Questionnaire (PPQ)						All	
							Missing		<= 24 (median)		> 24			
	N	%	N	%	N	%			N	%				
		N	%	N	%	N	%	N	%	N	%	N	%	N
Under \$20,000	2	3.2	2	2.5	3	3.8	2	3.3	1	2.0	4	3.6	7	3.2
\$20,000- \$29,999	0	0.0	2	2.5	4	5.1	0	0.0	2	4.1	4	3.6	6	2.7
\$30,000-- \$39,000	2	3.2	3	3.8	4	5.1	2	3.3	0	0.0	7	6.3	9	4.1
\$40,000 - \$49,000	3	4.8	6	7.5	5	6.3	4	6.7	2	4.1	8	7.1	14	6.3
\$50,000 - \$74,999	3	4.8	19	23.8	18	22.8	3	5.0	12	24.5	25	22.3	40	18.1
\$75,000 - \$99,999	7	11.3	20	25.0	16	20.3	4	6.7	16	32.7	23	20.5	43	19.5
\$100,000 - \$150,000	6	9.7	14	17.5	16	20.3	6	10.0	10	20.4	20	17.9	36	16.3
Over \$150,000	6	9.7	13	16.3	13	16.5	6	10.0	6	12.2	20	17.9	32	14.5
Gestational age														
< 28 weeks	3	4.8	24	30.0	35	44.3	3	5.0	15	30.6	44	39.3	62	28.1
28 to < 32 weeks	3	4.8	24	30.0	17	21.5	2	3.3	13	26.5	29	25.9	44	19.9
32 to < 37 weeks	1	1.6	19	23.8	15	19.0	0	0.0	12	24.5	23	20.5	35	15.8
37 to < 39 weeks	1	1.6	3	3.8	4	5.1	0	0.0	5	10.2	3	2.7	8	3.6
>= 39 weeks	0	0.0	3	3.8	1	1.3	0	0.0	1	2.0	3	2.7	4	1.8
Missing	54	87.1	7	8.8	7	8.9	55	91.7	3	6.1	10	8.9	68	30.8
Birth weight (grams)														
Missing	53	85.5	4	5.0	3	3.8	53	88.3	2	4.1	5	4.5	60	27.1
< 1000 grams	3	4.8	17	21.3	25	31.6	2	3.3	7	14.3	36	32.1	45	20.4
1000 to < 1500 grams	0	0.0	12	15.0	12	15.2	1	1.7	10	20.4	13	11.6	24	10.9
1500 to < 2500 grams	5	8.1	26	32.5	28	35.4	4	6.7	19	38.8	36	32.1	59	26.7
2500 to < 3500 grams	1	1.6	16	20.0	8	10.1	0	0.0	9	18.4	16	14.3	25	11.3
>= 3500 grams	0	0.0	5	6.3	3	3.8	0	0.0	2	4.1	6	5.4	8	3.6
Length of stay in NICU														
Missing	53	85.5	4	5.0	4	5.1	53	88.3	2	4.1	6	5.4	61	27.6
0 to 6 days	1	1.6	8	10.0	1	1.3	1	1.7	2	4.1	7	6.3	10	4.5
7 to 13 days	1	1.6	13	16.3	12	15.2	0	0.0	10	20.4	16	14.3	26	11.8
14 to 20 days	3	4.8	9	11.3	7	8.9	3	5.0	5	10.2	11	9.8	19	8.6
21 to 27 days	1	1.6	9	11.3	2	2.5	1	1.7	3	6.1	8	7.1	12	5.4
28 to 34 days	1	1.6	4	5.0	5	6.3	0	0.0	3	6.1	7	6.3	10	4.5
35 to 49 days	0	0.0	8	10.0	7	8.9	0	0.0	7	14.3	8	7.1	15	6.8
50 to 74 days	1	1.6	6	7.5	14	17.7	1	1.7	5	10.2	15	13.4	21	9.5
75 to 99 days	0	0.0	8	10.0	8	10.1	1	1.7	4	8.2	11	9.8	16	7.2
100 to 124 days	1	1.6	6	7.5	6	7.6	0	0.0	3	6.1	10	8.9	13	5.9
125 to 149 days	0	0.0	2	2.5	4	5.1	0	0.0	2	4.1	4	3.6	6	2.7
150 days or more	0	0.0	3	3.8	9	11.4	0	0.0	3	6.1	9	8.0	12	5.4

Table 2: Descriptives for each section of the PSS: NICU by demographic information

	Parental Stress Scale: Sights and Sounds				Parental Stress Scale: Baby Looks and Behaves /Treatments done to Baby				Parental Stress Scale: Relationship with Baby/Parental role			
	N	Q1	Median	Q3	N	Q1	Median	Q3	N	Q1	Median	Q3
<b>Maternal age</b>												
28 to <26	8	2.00	2.00	7.00	7	6.00	12.00	20.00	8	0.00	2.00	6.00
26 to < 35	91	4.00	6.00	8.00	93	8.00	14.00	22.00	93	0.00	4.00	8.00
35+	62	4.00	6.00	8.00	62	8.00	16.00	20.00	63	2.00	4.00	10.00
Missing	0	0	0	0	0	0	0	0	0	0	0	0
<b>Race/Ethnicity</b>												
White	154	4.00	6.00	8.00	154	8.00	14.00	20.00	156	0.00	4.00	8.00
Asian	1	8.00	8.00	8.00	1	4.00	4.00	4.00	1	4.00	4.00	4.00
Black or African American	2	4.00	4.00	4.00	3	12.00	20.00	24.00	3	4.00	8.00	10.00
Other	2	2.00	5.00	8.00	2	16.00	20.00	24.00	2	4.00	6.00	8.00
White, American Indian or Alaska Native	1	10.00	10.00	10.00	1	16.00	16.00	16.00	1	4.00	4.00	4.00
White, other	0	0	0	0	0	0	0	0	0	0	0	0
Black or African American, White, American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander	1	12.00	12.00	12.00	1	10.00	10.00	10.00	1	8.00	8.00	8.00
Missing	0	0	0	0	0	0	0	0	0	0	0	0
<b>What is the highest level of education you have completed?</b>												
missing	0	0	0	0	0	0	0	0	0	0	0	0
High school	28	2.00	5.00	10.00	29	12.00	16.00	24.00	29	0.00	4.00	8.00
Associates degree (AA, AS, etc)	13	4.00	6.00	8.00	13	10.00	16.00	20.00	13	0.00	4.00	8.00
Baccalaureate degree (BA, BS, BSBA, etc)	73	4.00	6.00	8.00	73	8.00	14.00	20.00	74	0.00	4.00	8.00
Masters degree (MA, MS, etc)	39	4.00	6.00	8.00	39	8.00	16.00	22.00	40	3.00	4.00	9.00
Doctoral or Professional degree (PhD, MD, JD, DDS, etc)	8	4.00	6.00	7.00	8	3.00	7.00	13.00	8	4.00	8.00	12.00
<b>What was your total household income, before taxes, in 2012?</b>												
Missing	1	6.00	6.00	6.00	1	14.00	14.00	14.00	1	2.00	2.00	2.00
Under \$20,000	5	4.00	6.00	8.00	6	12.00	17.00	20.00	6	4.00	4.00	8.00
\$20,000 - \$29,999	6	4.00	6.00	12.00	6	18.00	21.00	24.00	6	0.00	2.00	8.00
\$30,000 - \$39,000	7	4.00	8.00	10.00	7	10.00	14.00	26.00	7	0.00	8.00	24.00
\$40,000 - \$49,000	11	2.00	6.00	8.00	11	8.00	16.00	20.00	11	0.00	4.00	8.00
\$50,000 - \$74,999	37	4.00	6.00	8.00	37	8.00	14.00	20.00	37	0.00	4.00	10.00
\$75,000 - \$99,999	37	2.00	4.00	8.00	38	8.00	13.00	18.00	39	0.00	4.00	8.00
\$100,000 - \$150,000	30	4.00	6.00	12.00	30	10.00	15.00	22.00	30	2.00	5.00	8.00
Over \$150,000	27	2.00	6.00	8.00	26	4.00	11.00	22.00	27	4.00	8.00	10.00
<b>Gestational age</b>												
< 28 weeks	59	4.00	6.00	8.00	61	10.00	18.00	24.00	61	2.00	4.00	10.00
28 to < 32 weeks	42	4.00	6.00	8.00	41	8.00	14.00	20.00	42	0.00	4.00	8.00
32 to < 37 weeks	34	2.00	4.00	8.00	35	4.00	12.00	18.00	35	0.00	6.00	10.00
37 to < 39 weeks	8	3.00	5.00	7.00	7	8.00	14.00	18.00	8	2.00	6.00	12.00

	Parental Stress Scale: Sights and Sounds				Parental Stress Scale: Baby Looks and Behaves /Treatments done to Baby				Parental Stress Scale: Relationship with Baby/Parental role			
	N	Q1	Median	Q3	N	Q1	Median	Q3	N	Q1	Median	Q3
>= 39 weeks	4	6.00	7.00	10.00	4	3.00	7.00	12.00	4	0.00	3.00	9.00
Missing	14	4.00	6.00	10.00	14	0.00	14.00	20.00	14	0.00	4.00	8.00
Birth weight (grams)												
Missing	7	4.00	6.00	12.00	7	0.00	8.00	18.00	7	0.00	2.00	8.00
< 1000 grams	42	4.00	6.00	8.00	44	8.00	17.00	24.00	44	0.00	4.00	9.00
1000 to < 1500 grams	24	2.00	5.00	7.00	24	11.00	18.00	23.00	24	3.00	7.00	10.00
1500 to < 2500 grams	55	4.00	4.00	8.00	55	10.00	14.00	20.00	56	0.00	5.00	8.00
2500 to < 3500 grams	25	2.00	4.00	8.00	24	5.00	12.00	17.00	25	0.00	4.00	8.00
>= 3500 grams	8	6.00	7.00	10.00	8	2.00	7.00	11.00	8	0.00	7.00	10.00
Length of stay in NICU												
Missing	8	4.00	6.00	11.00	8	0.00	10.00	18.00	8	0.00	3.00	8.00
0 to 6 days	9	2.00	4.00	8.00	9	0.00	6.00	14.00	9	0.00	0.00	4.00
7 to 13 days	26	2.00	5.00	8.00	25	4.00	12.00	18.00	26	0.00	6.00	10.00
14 to 20 days	16	4.00	4.00	8.00	17	8.00	14.00	20.00	17	0.00	6.00	8.00
21 to 27 days	11	2.00	4.00	6.00	11	8.00	12.00	18.00	11	0.00	4.00	10.00
28 to 34 days	10	4.00	6.00	8.00	9	10.00	16.00	20.00	10	2.00	7.00	12.00
35 to 49 days	15	2.00	4.00	8.00	15	10.00	16.00	20.00	15	4.00	8.00	12.00
50 to 74 days	20	3.00	6.00	8.00	21	14.00	20.00	24.00	21	0.00	4.00	8.00
75 to 99 days	16	4.00	6.00	8.00	16	6.00	11.00	17.00	16	0.00	4.00	9.00
100 to 124 days	12	4.00	7.00	8.00	13	8.00	18.00	26.00	13	4.00	4.00	12.00
125 to 149 days	6	6.00	7.00	14.00	6	12.00	17.00	24.00	6	4.00	8.00	12.00
150 days or more	12	3.00	6.00	8.00	12	16.00	21.00	24.00	12	1.00	4.00	8.00
Overall	161	4.00	6.00	8.00	162	8.00	14.00	20.00	164	0.00	4.00	8.00

**Table 3: Healthcare Seeking Behaviors by Score**

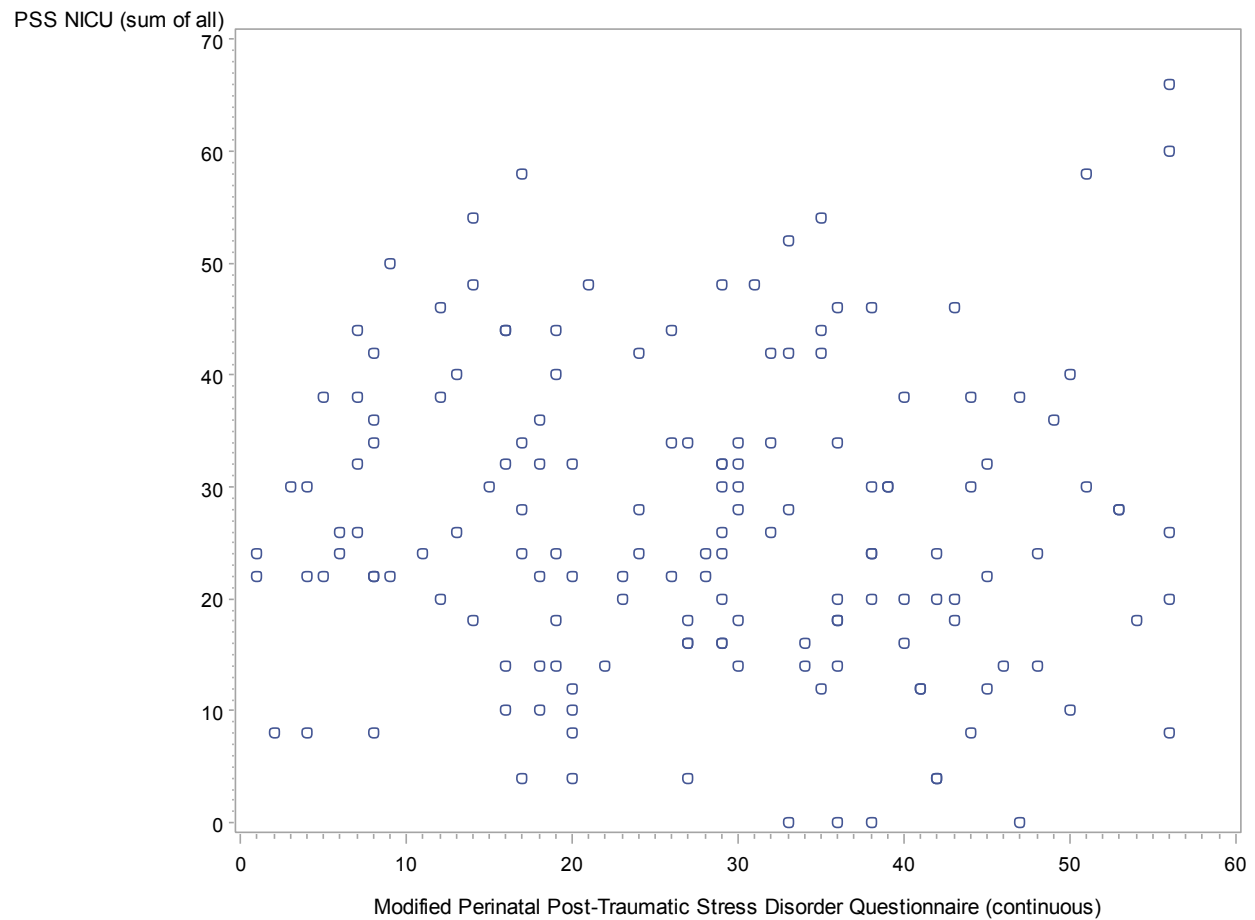
hsb	Frequency	Percent
1	7	34.35
2	30	118.6
3	56	34.7
4	68	43.23

**Table 4: Healthcare Seeking Behavior exhibited by NICU MOM**

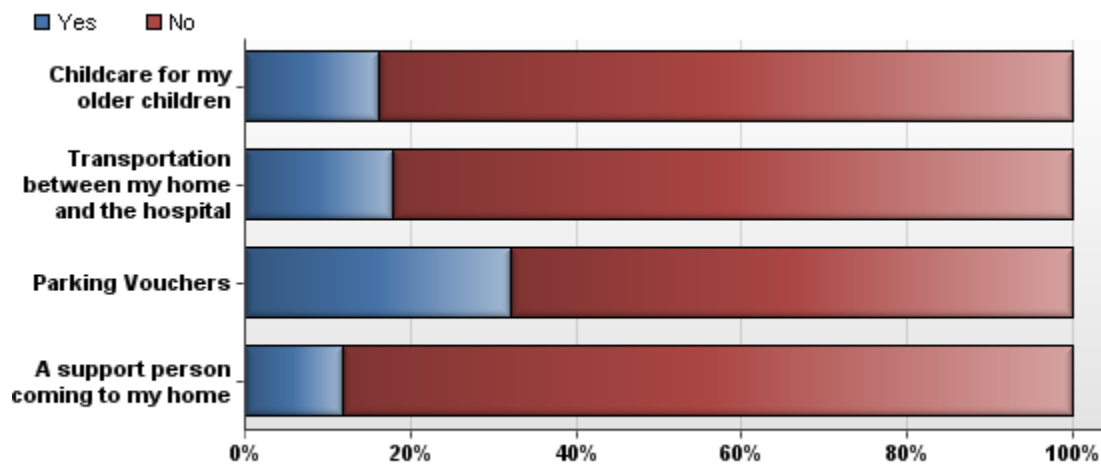
Variable	Variable level	Reference level	OR (95% CI)	p-value
Screened and treated	Yes	No	1.6 (0.54,4.72)	0.3965

Variable	Variable level	Reference level	OR (95% CI)	p-value
PTSD	Elevated ( $\geq 19$ )	Not elevated ( $< 19$ )	0.33 (0.15,0.72)	0.0048
Days in the NICU (continuous)			1.02 (0.91,1.14)	0.7613
Maternal age (continuous)			0.97 (0.9,1.05)	0.4963
Highest level of education	Associates degree (AA, AS, etc)	High school	1.34 (0.26,6.95)	0.7278
Highest level of education	Baccalaureate degree (BA, BS, BSBA, etc)	High school	2.6 (0.92,7.34)	0.0704
Highest level of education	Doctoral or Professional degree (PhD, MD, JD, DDS, etc)	High school	4.83 (0.8,29.24)	0.0868
Highest level of education	Masters degree (MA, MS, etc)	High school	3.9 (1.2,12.63)	0.0232

**Figure 1: Total PSS:NICU Scores versus Total Modified Perinatal Post-Traumatic Stress Disorder (PTSD) Questionnaire (PPQ)**  
**Plot of PSS:NICU versus PTSD**



**Figure 2: Did you have any of the following services while your baby was in the NICU?**



Of women completing this question N answered the following:

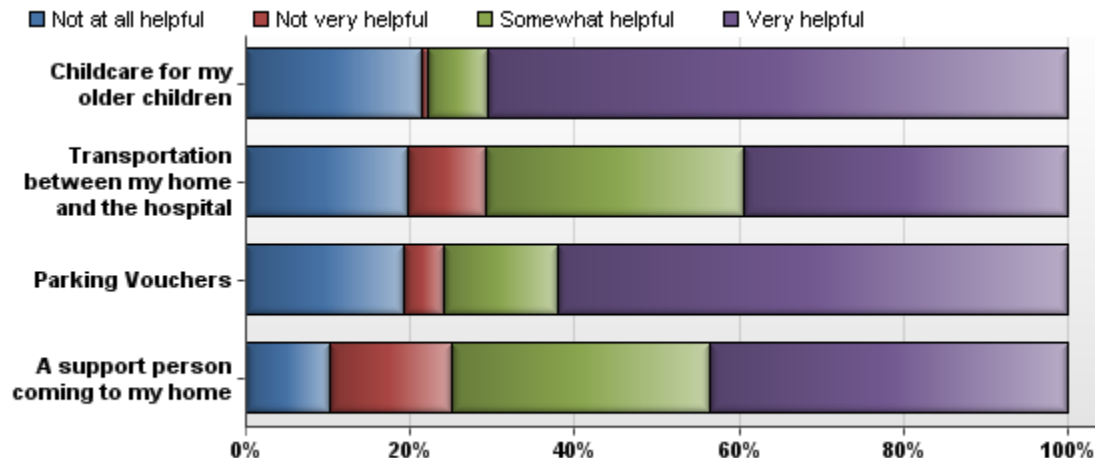
Childcare for my older children: N= 142

Transportation between my home and the hospital: N=152

Parking Vouchers: N= 153

A support person coming to my home: N= 152

**Figure 3: How helpful was it or would it be to have the following services while you were participating in a program for NICU parents?**



**Of women completing this question N answered the following:**

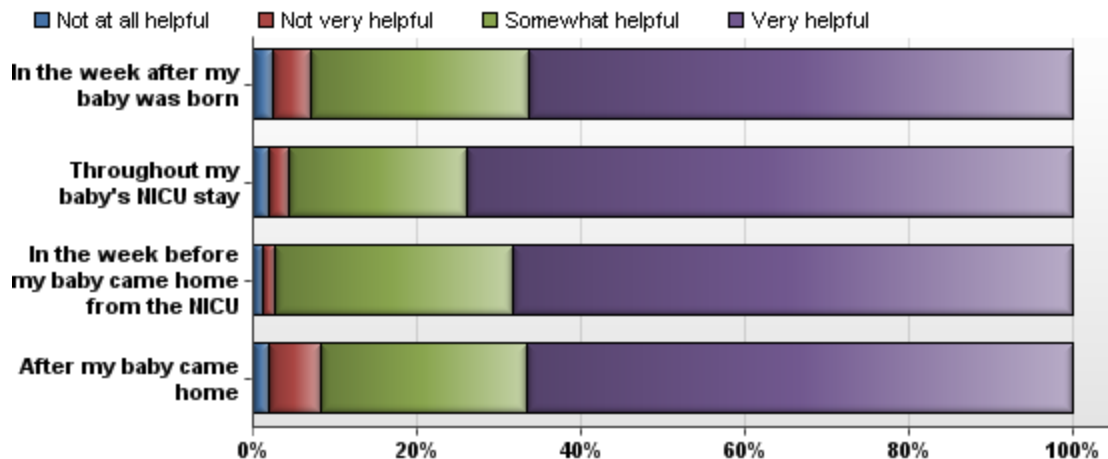
Childcare for my older children: N+ 136

Transportation between my home and the hospital: N=147

Parking Vouchers: N=145

A support person coming to my home: N=147

**Figure 4: How helpful would a support program for NICU families be at the following times?**



**Of women completing this question N answered the following:**

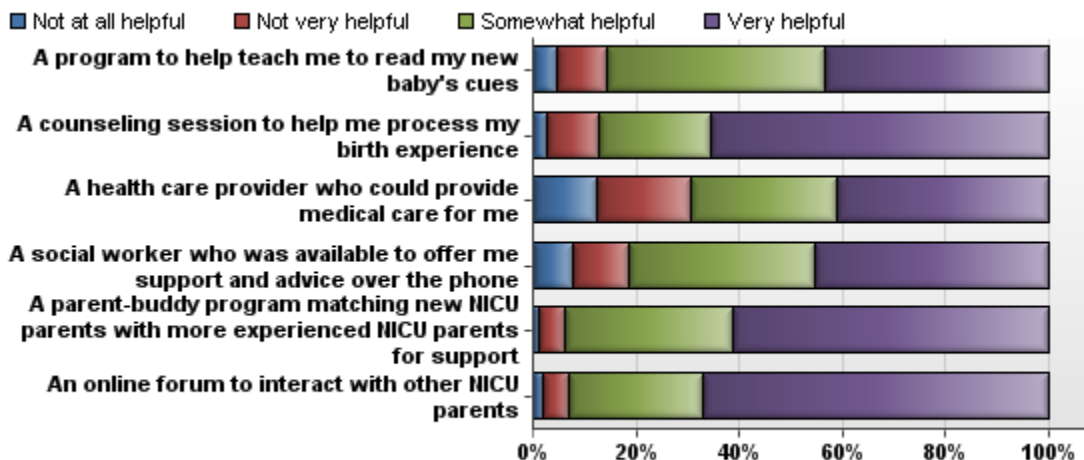
In the week after my baby was born: N=157

Throughout my baby's NICU stay: N=157

In the week before my baby came home from the NICU: N=154

After my baby came home: N=156

**Figure 5: How helpful would you have found the following programs while you had a baby in the NICU?**



**Of women completing this question, N answered the following:**

A program to help teach me to read my new baby's cues: N=155

A counseling session to help me process my birth experience: N=156

A health care provider who could provide medical care for me: N= 153

A social worker who was available to offer me support and advice over the phone: N=156



A parent-buddy program matching new NICU parents with more experienced NICU parents for support: N=157

An online forum to interact with other NICU parents: N=155

## NICU MOMs Online September 3 to Give out

Q77 Thank you for taking the time to complete this survey to help us learn more about the experience of mothers who have had a baby in the Neonatal Intensive Care Unit (NICU). Researchers at the University of North Carolina at Chapel Hill are interested in creating programs to help make sure NICU mothers are getting the health care and support they need. This survey is part of a research study. It will help us understand what challenges you faced while your baby was (or babies were) in the NICU and once you returned home, and what kinds of services would provide the best support to other mothers. Some of the questions are sensitive and personal in nature. All of the survey responses are anonymous. You may skip any questions you prefer not to answer. If you are unable to complete the survey in one sitting, you may come back and complete it within the month. Your participation is voluntary and you may quit the survey at any times. This survey should take you approximately 30 minutes to complete. To participate in this survey, you must be at least 18 years of age, be comfortable reading English and have given birth to a child that spent at least 7 days in the NICU.

Q120 Please complete the following questions about yourself.

Q78 By clicking yes, you agree to participate in this study.

☐ Yes (1)

☐ No (2)

If No Is Selected, Then Skip To End of Survey

Q64 Did you give birth to a child that spent more than 6 days in the NICU within the past 5 years.

☐ Yes (1)

☐ No (2)

If No Is Selected, Then Skip To End of Survey

Q128 To start off, please share some information about you and your household.

Q127 How old are you?

- ☐ 18 (1)
- ☐ 19 (2)
- ☐ 20 (3)
- ☐ 21 (4)
- ☐ 22 (5)
- ☐ 23 (6)
- ☐ 24 (7)
- ☐ 25 (8)
- ☐ 26 (9)
- ☐ 27 (10)
- ☐ 28 (11)
- ☐ 29 (12)
- ☐ 30 (13)
- ☐ 31 (14)
- ☐ 32 (15)
- ☐ 33 (16)
- ☐ 34 (17)
- ☐ 35 (18)
- ☐ 36 (19)
- ☐ 37 (20)
- ☐ 38 (21)
- ☐ 39 (22)
- ☐ 40 (23)
- ☐ 41 (24)
- ☐ 42 (25)
- ☐ 43 (26)
- ☐ 44 (27)
- ☐ 45 (28)
- ☐ 46 (29)
- ☐ 47 (30)
- ☐ 48 (31)
- ☐ 49 (32)
- ☐ 50 (33)
- ☐ 51 (34)
- ☐ 52 (35)
- ☐ 53 (36)
- ☐ 54 (37)

- ☐ 55 (38)
- ☐ 56 (39)
- ☐ 57 (40)
- ☐ 58 (41)
- ☐ 59 (42)
- ☐ 60 (43)

Q126 Are you of Hispanic or Latino origin?

- ☐ Yes (1)
- ☐ No (2)

Q125 What racial groups do you identify with? Please select all that apply.

- ☐ Black or African American (1)
- ☐ White (2)
- ☐ Asian (3)
- ☐ American Indian or Alaska Native (4)
- ☐ Native Hawaiian or Other Pacific Islander (5)
- ☐ Some other race, please specify: (6) \_\_\_\_\_

Q134 What language do you most often speak at home?

- ☐ English (1)
- ☐ Spanish (2)
- ☐ Other, please specify: (3) \_\_\_\_\_

Q135 What is your current relationship status. Please check all that apply.

- ☐ Single (1)
- ☐ Married (2)
- ☐ Divorced (3)
- ☐ Widowed (4)
- ☐ Living with a romantic partner (5)

Q136 What is the highest level of education you have completed?

- ☐ Less than high school (1)
- ☐ High school (2)
- ☐ Associates degree (AA, AS, etc) (3)
- ☐ Baccalaureate degree (BA, BS, BSBA, etc) (4)
- ☐ Masters degree (MA, MS, etc) (5)
- ☐ Doctoral or Professional degree (PhD, MD, JD, DDS, etc) (6)

Q121 What was your total household income, before taxes, in 2012?

- ☐ Under \$20,000 (1)
- ☐ \$20,000 – \$29,999 (2)
- ☐ \$30,000-- \$39,000 (3)
- ☐ \$40,000 - \$49,000 (4)
- ☐ \$50,000 - \$74,999 (5)
- ☐ \$75,000 - \$99,999 (6)
- ☐ \$100,000 - \$150,000 (7)
- ☐ Over \$150,000 (8)

Q3 How do you most often access the internet in your home?

- ☐ Computer or laptop using dial-up internet (1)
- ☐ Computer or laptop using high speed internet (2)
- ☐ Tablet (3)
- ☐ Smartphone (4)
- ☐ Other (5) \_\_\_\_\_

Q137 How many adults aged 18 or older live in your household? Please include yourself in the total.

- ☐ 1 (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (7)
- ☐ 8 (8)
- ☐ 9 (9)
- ☐ 10 (10)
- ☐ More than 10 (11)

Q138 How many children under the age of 18 live in your household?

- ☐ 1 (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (7)
- ☐ 8 (8)
- ☐ 9 (9)

- ☐ 10 (10)
- ☐ More than 10 (11)

Q139 Of the children under the age of 18 living in your household, how old is the oldest child?

- ☐ 1 (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (7)
- ☐ 8 (8)
- ☐ 9 (9)
- ☐ 10 (10)
- ☐ 11 (11)
- ☐ 12 (12)
- ☐ 13 (13)
- ☐ 14 (14)
- ☐ 15 (15)
- ☐ 16 (16)
- ☐ 17 (17)

Q141 Of the children under the age of 18 living in your household, how old is the youngest child?

- ☐ Less than 1 (1)
- ☐ 1 (2)
- ☐ 2 (3)
- ☐ 3 (4)
- ☐ 4 (5)
- ☐ 5 (6)
- ☐ 6 (7)
- ☐ 7 (8)
- ☐ 8 (9)
- ☐ 9 (10)
- ☐ 10 (11)
- ☐ 11 (12)
- ☐ 12 (13)
- ☐ 13 (14)
- ☐ 14 (15)
- ☐ 15 (16)
- ☐ 16 (17)
- ☐ 17 (18)

Q149 Please answer the following questions about your pregnancy history.

Q144 During your lifetime, how many times have you been pregnant? Please include all pregnancies regardless of outcome(s).

- ☐ 1 (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (7)
- ☐ 8 (8)
- ☐ 9 (9)
- ☐ 10 (10)
- ☐ More than 10 (11)

Q161 What was the result of each of your pregnancies? Please check all that apply.

	Live birth at 37 weeks or later (1)	Live birth at less than 37 weeks (2)	Miscarriage (less than 20 weeks) (3)	Still birth (greater than 20 weeks) (4)	Abortion (5)	Ectopic pregnancy (6)	Baby was admitted to the NICU (7)
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Q167 How many pregnancies have you had that resulted in babies spending more than 6 days in the NICU? Please enter in a number (eg. 1, 2, 3 etc).

Q164 On your  $\{\text{lm://Field/2}\}$  pregnancy that resulted in a NICU baby, how many babies did you have?

- ☐ 1 (singleton) (1)
- ☐ 2 (twins) (2)
- ☐ 3 (triplets) (3)
- ☐ 4 (quadruplets) (4)
- ☐ 5 or more. Please enter the number below (5) \_\_\_\_\_

If 5 or more. Please enter the... Is Selected, Then Skip To Please share with us some details abo...If 5 or more. Please enter the... Is Greater Than or Equal to 5, Then Skip To Please share with us some details abo...

Q88 Concerning your  $\{\text{lm://Field/2}\}$  pregnancy that resulted with a baby in the NICU, what day was your baby's due date?

	Month	Day	
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Q143 Concerning your  $\{\text{lm://Field/2}\}$  pregnancy that resulted with a baby in the NICU, what day was your baby born?

	Month	Day	
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Q165 Concerning your pregnancy that resulted with a baby in the NICU, how was your baby delivered?

	Vaginally (1)	Cesarian Section (C-section) (2)
First child from this pregnancy (1)	<input type="radio"/>	<input type="radio"/>
Second child from this pregnancy (2)	<input type="radio"/>	<input type="radio"/>
Third child from this pregnancy (3)	<input type="radio"/>	<input type="radio"/>
Fourth child from this pregnancy (4)	<input type="radio"/>	<input type="radio"/>

Q87 Concerning your pregnancy that resulted with a baby in the NICU, how much did your baby weigh at birth?

	Pounds (lbs)	Ounces
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Q89 Concerning your pregnancy, why was your baby admitted to the NICU? Please check all that apply.

	Birth Defect (1)	Infection (2)	Breathing Problems (3)	Born Early (4)	Low Birthweight (5)	Other (6)	Baby was not admitted to the NICU (7)
First child from this pregnancy (9)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Second child from this pregnancy (10)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Third child from this pregnancy (11)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fourth child from this pregnancy (12)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Answer If Concerning your pregnancy, why was your b... First child - Other Is Selected Or Concerning your pregnancy, why was your b... Second child - Other Is Selected Or Concerning your pregnancy, why was your b... Third child - Other Is Selected Or Concerning your pregnancy, why was your b... Fourth child - Other Is Selected

Q125 Please explain the other reasons your baby was admitted to the NICU.

Q55 Concerning your pregnancy, how long was your baby in the NICU? Please give a numeric answer in days.

	Days (1)
First child from this pregnancy (1)	
Second child from this pregnancy (2)	
Third child from this pregnancy (3)	
Fourth child from this pregnancy (4)	

Q160 Is your baby still living?

	Yes (1)	No (2)
First child from this pregnancy (30)	<input type="radio"/>	<input type="radio"/>
Second child from this pregnancy (31)	<input type="radio"/>	<input type="radio"/>
Third child from this pregnancy (32)	<input type="radio"/>	<input type="radio"/>
Fourth child from this pregnancy (33)	<input type="radio"/>	<input type="radio"/>

Answer If Is your baby still living? First child - Yes Is Selected Or Is your baby still living? Second child - Yes Is Selected Or Is your baby still living? Third child - Yes Is Selected Or Is your baby still living? Fourth child - Yes Is Selected

Q74 Does your child currently have health problems related to the reason he or she was in the NICU?

Answer If Is your baby still living? First child - No Is Selected Or Is your baby still living? Second child - No Is Selected Or Is your baby still living? Third child - No Is Selected Or Is your baby still living? Fourth child - No Is Selected

Q159 Did your child pass away because of the reason he or she was in the NICU?

Answer If On your  pregnancy that resulted in ... 5 or more. Please enter the number below Is Selected Or On your  pregnancy that resulted in ... 5 or more. Please enter the number below Is Greater Than or Equal to 5

Q124 Please share with us some details about your pregnancy that resulted in 5 or more babies. How much did they weigh at birth? Why were they admitted to the NICU? How long were your babies in the NICU?

Q110 Please answer the following questions about your pregnancy and NICU experience regarding your baby that was most recently in the NICU.

Q29 Were you hospitalized for any problems during this pregnancy?

- ☐ Yes (1)
- ☐ No (2)

Answer If Were you hospitalized for any problems during your pregna... Yes Is Selected

Q30 How many nights did you spend in the hospital before your baby was born? Please give total number of nights spent at the hospital. Please give a numeric answer.

Answer If Were you hospitalized for any problems during this pregna... Yes Is Selected

Q132 Why were you admitted to the hospital prior to the birth of your NICU baby? Please check all that apply.

- ☐ Preterm labor (1)
- ☐ Water broke early (2)
- ☐ Blood pressure (3)
- ☐ Bleeding (4)
- ☐ Other (5) \_\_\_\_\_

Q61 In what country was the NICU located? If USA, what state?

Answer If In what country was the NICU located? If USA, what state? - USA ~ North Carolina Is Selected

Q65 My child spent time at the NICU at UNC Hospital in Chapel Hill, North Carolina.

- ☐ Yes (1)
- ☐ No (2)

Answer If My child spent time at the NICU at UNC Hospital in Chapel... Yes Is Selected

Q126 Did you taken a paper survey similar to this survey?

- ☐ Yes (1)
- ☐ No (2)

Q59 How long did it take you to travel to visit the NICU from your home? Please answer in minutes.

Q104 While your baby was in the NICU, did you spend the night at the following places?  
Please check all that apply.

- ☐ At my own home (1)
- ☐ Ronald McDonald House (2)
- ☐ With family or friends (3)
- ☐ Single family room in the NICU (4)
- ☐ Boarding room at the hospital (5)
- ☐ Hotel (6)
- ☐ Other (7) \_\_\_\_\_

Q130 Please choose the option that best described your smoking status during your pregnancy with your NICU baby.

- ☐ You have NEVER smoked or smoked less than 100 cigarettes in your lifetime. (1)
- ☐ You stopped smoking BEFORE you found out you were pregnant and are NOT smoking now. (2)
- ☐ You stopped smoking AFTER you found out you were pregnant and are NOT smoking now. (3)
- ☐ You stopped smoking while you were pregnant, but you are smoking now. (4)
- ☐ You smoked during your pregnancy, and you are smoking now. (5)

Q131 Did anyone smoke around you (in your home, in your car, or workplace) when you were pregnant with your NICU baby?

- ☐ Yes (1)
- ☐ No (2)

Q183 Did you work for pay during the pregnancy with your child who spent time in the NICU?

- ☐ Yes, I worked full-time. (1)
- ☐ Yes, I worked part-time. (2)
- ☐ No (3)

Q185 Did your job include paid maternity leave?

- ☐ Yes, I had paid maternity leave (1)
- ☐ No, but I did have unpaid maternity leave (2)
- ☐ No, I did not have maternity leave but took disability leave (3)
- ☐ No, I did not have any maternity leave. (4)
- ☐ Other (5) \_\_\_\_\_

Q187 Do you work for pay now?

- ☐ Yes (1)  
☐ Yes, but still on maternity leave (2)  
☐ No (3)  
☐ Other (4) \_\_\_\_\_

Answer If Do you work for pay now? Yes, but the same number of hours as before pregnancy Is Selected

Q189 How many hours per week do you usually work at your job? Please give a numeric answer.

Answer If Do you work for pay now? Yes Is Selected

Q191 How old was your child who had been in the NICU when you returned to work? Please give a numeric answer.

Months (1)

Years (2)

Q57 Below is a list of items that might describe the way your BABY LOOKS AND BEHAVES while you are/were visiting in the NICU as well as some of the TREATMENTS that you have seen done to your baby. Not all babies have these experiences or look this way, so choose the "not applicable" 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.

	Not at all stressful (1)	A little stressful (2)	Moderately stressful (3)	Very stressful (4)	Extremely stressful (5)	Not Applicable (6)
Tubes and equipment on or near my baby (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bruises, cuts or incisions on my baby (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The unusual color of my baby (for example, looking pale or yellow jaundiced) (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My baby's unusual or abnormal breathing patterns (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The small size of my baby (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The wrinkled appearance of my baby (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having a machine (respirator) breathe for my baby (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seeing needles and tubes put in my baby (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My baby being fed by an intravenous line or tube (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my baby seemed to be in pain (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When my baby looked sad (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The limp and weak appearance of my baby (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Jerky or restless movements of my baby (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My baby not being able to cry like other babies (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q56 Below is a list of the various SIGHTS AND SOUNDS commonly experienced in an NICU. We are interesting in knowing about your view of how stressful these SIGHTS AND SOUNDS are/ were for you. Choose the option that best represents your level of stress while in the NICU.

	Not at all stressful (1)	A little stressful (2)	Moderately stressful (3)	Very stressful (4)	Extremely stressful (5)	Not Applicable (6)
The presence of monitors and equipment (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The constant noises of monitors and equipment (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The sudden noises of monitor alarms (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The other sick babies in the room (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The large number of people working in the unit (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q58 How do you feel about your own RELATIONSHIP with the baby and your PARENTAL ROLE. If you have experienced the following situations or feelings, indicate how stressed you have been by them by clicking the circle. Again, choose Not Applicable if you did not experience the item.

	Not at all stressful (1)	A little stressful (2)	Moderately stressful (3)	Very stressful (4)	Extremely stressful (5)	Not Applicable (6)
Being separated from my baby (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not feeding my baby myself (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not being able to care for my baby myself (for example, diapering, bathing) (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not being able to hold my baby when I want (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling helpless and unable to protect my baby from pain and painful procedures (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling helpless about how to help my baby during this time (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not having time alone with my baby (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Q52 Thinking about when your baby was in the NICU, did you experience the the following statements?

	Not at all (1)	Once or twice (2)	Sometimes (3)	Often, but for less than 1 month post birth (4)	Often, going on more than a month after birth (5)
Did you have bad dreams of giving birth or of your baby's hospital stay? (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have upsetting memories of giving birth or of your baby's hospital stay? (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have any sudden feelings as though your baby's birth was happening again? (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you try to avoid thinking about childbirth or your baby's hospital stay? (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you avoid doing things that might bring up feelings you had about childbirth or your baby's hospital stay? (e.g. not watching a TV show about babies) (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were you unable to remember parts of your baby's hospital stay? (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you lose interest in doing things you usually do? (e.g. did you lose interest in your work or family?) (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel alone and removed from other people? (e.g. did you feel like no one understood you?) (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did it become more difficult for you to feel tenderness or love with others? (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have unusual difficulty falling asleep or staying asleep? (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were you more irritable or angry with others than usual? (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did you have greater difficulties concentration than before you gave birth? (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel more jumpy? (e.g. did you feel more sensitive to noise, or more easily startled?) (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel more guilt about the childbirth experience than you felt you should have felt? (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q4 Would you currently have the kinds of help listed below if you needed them?

	No (1)	Yes (2)
Someone to loan me \$50 (1)	<input type="radio"/>	<input type="radio"/>
Someone to help me if I were sick and needed to be in bed (2)	<input type="radio"/>	<input type="radio"/>
Someone to take me to the clinic or doctor's office if I needed a ride (3)	<input type="radio"/>	<input type="radio"/>
Someone to talk with about my problems (4)	<input type="radio"/>	<input type="radio"/>

Q124 The next questions relate you your healthcare and healthcare access during the 12 months following the birth of your NICU baby. If you had more than one NICU baby, please answer the following questions based on the year following the birth of your baby that was most recently in the NICU. If your baby was in the NICU within the past 12 months, please answer the questions based on your current healthcare and healthcare access.

Q31 Is there a place that you were able to go when you were sick, need advice about your health, or want to get a routine check-up?

- ☐ Yes (1)
- ☐ There is more than one place (2)
- ☐ No (3)

Answer If Is there a place that you were able to go when you were s... No Is Not Selected

Q32 What kind of place did you go most often?

- ☐ County health department (1)
- ☐ Other clinic or health center (2)
- ☐ Urgent Care/ Minute Clinic (3)
- ☐ Doctor's office-general practitioner (4)
- ☐ Doctor's office- Ob-gyn (5)
- ☐ Doctor's office-specialist (6)
- ☐ Hospital emergency room (7)
- ☐ Hospital outpatient department (8)
- ☐ Some other place, please specify: (9) \_\_\_\_\_

Q33 A personal health care provider is a health professional who knows you well and is familiar with your health history. This can be a general doctor, a specialist, a nurse practitioner, or another type of provider. Did you have a person you thought of as your personal doctor or health care provider?

- ☐ Yes (1)
- ☐ No (2)

Q34 What kind of medical care coverage did you have within the 12 months of the birth of your NICU baby? Please check all that apply.

- ☐ None (uninsured) (1)
- ☐ Private insurance from you or your partner's employer (2)
- ☐ Private insurance from your parent's employer (3)
- ☐ Private insurance you purchased directly from an insurance company (4)
- ☐ Medicaid or other publicly funded insurance (5)
- ☐ Pregnancy Medicaid (6)
- ☐ Other, please specify: (7) \_\_\_\_\_

Q35 During the 12 months following the birth of your NICU baby, did you delay or put off medical care for yourself for any reason?

- ☐ Yes (1)
- ☐ No (2)

Answer If During the past year, have you delayed or put off medical... Yes Is Selected

Q36 How important were each of the following reasons for delaying or putting off care?

	Not at all Important (1)	Not very Important (2)	Somewhat Important (3)	Very Important (4)
I didn't know where to go (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't get around to it/ was too busy (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical care was far away/ not convenient (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seeing a health care provider makes me feel uncomfortable or embarrassed (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I couldn't get through on the telephone (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I couldn't make an appointment at a convenient time (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Once I got there, I had to wait too long to see the doctor (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't have transportation (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't have child care (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It was too expensive (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q37 During the 12 months following the birth of your NICU baby, was there any time you needed any of the following? Please choose all that apply:

- ☐ Prescription medications (1)
- ☐ Mental health care or counseling (2)
- ☐ Dental care (3)
- ☐ Follow-up care (4)
- ☐ Birth control (5)

Answer If During the past year, was there any time you needed any o...

q://QID37/SelectedChoicesCount Is Greater Than or Equal to 1

Q38 Were you unable to access any of these services because you couldn't afford them? Please choose all that apply:

- ☐ Prescription medications (1)
- ☐ Mental health care or counseling (2)
- ☐ Dental care (3)
- ☐ Follow-up care (4)
- ☐ Birth control (5)

Q39 In the 12 months following the delivery of your NICU baby, did you have difficulty understanding what your doctor or other health care provider was telling you about your healthcare?

- ☐ Yes (1)
- ☐ No (2)

Q40 If you gave birth more than 6 weeks ago, did you have a postpartum check-up with a health care provider?

- ☐ Yes (1)
- ☐ No (2)
- ☐ I gave birth less than 6 weeks ago (3)

Q128 Were you screened for postpartum depression?

- ☐ Yes (1)
- ☐ No (2)

Q129 Were you diagnosed with postpartum depression?

- ☐ Yes (1)
- ☐ No (2)

Answer If Were you diagnosed with postpartum depression? Yes Is Selected

Q130 What help did you receive for your postpartum depression? Please check all that apply.

- ☐ Therapy (1)
- ☐ Prescription Medication (2)
- ☐ Support Group- In person (3)
- ☐ Support Group- Online (4)
- ☐ None (5)
- ☐ Other (6) \_\_\_\_\_

Q97 Breastfeeding can be challenging for any mother, and we know it can be especially challenging for NICU moms and babies. The next set of questions concerns your breastfeeding experience concerning your NICU baby. If you have had more than 1 baby in the NICU, please answer these questions about your baby that was most recently in the NICU.

Q81 Did you ever breastfeed your NICU baby?

- ☐ Yes (1)
- ☐ No (2)

Answer If Did you ever breastfeed your NICU baby? Yes Is Selected

Q79 Are you currently breastfeeding your NICU baby or feeding your baby pumped milk? Please check all that apply.

- ☐ Yes, I am currently breastfeeding my baby. (1)
- ☐ Yes, I am currently feeding my baby pumped milk. (3)
- ☐ No (4)

If 2 Is Selected, Then Skip To Did you breastfeed as long as you wan...

Answer If Are you currently breastfeeding your NICU baby or feeding... Yes Is Selected

Q105 How many times a day are you pumping? Please enter a numeric value. If none, please enter 0.

Answer If Are you currently breastfeeding your NICU baby or feeding... Yes Is Selected

Q80 In the past 24 hours, how many times did you feed your baby in the each of the following ways? Please fill in the number of feedings. If they did not occur, please fill in 0.

- Breastfed (1)
- Fed pumped milk (2)
- Fed infant formula (3)
- Fed solid foods (4)

Answer If Are you currently breastfeeding your NICU baby or feeding... No Is Selected

Q82 Did you breastfeed as long as you wanted to?

- ☐ Yes (1)
- ☐ No (2)

Q86 Has your baby ever had formula?

- ☐ Yes (1)
- ☐ No (2)

Answer If How your baby ever had formula? Yes Is Selected

Q84 How old was your baby when he or she was first fed formula? Please enter values for one unit.

- Days (1)
- Months (2)
- Weeks (3)
- Years (4)

Answer If Are you currently breastfeeding your NICU baby or feeding... No Is Selected

Q83 How old was your baby when you completely stopped breastfeeding and pumping milk? Please enter values for one unit.

- Days (1)
- Weeks (2)
- Months (3)
- Years (4)

Answer If Are you currently breastfeeding your NICU baby or feeding... No Is Selected

Q85 How important were each of the following reasons you stopped breastfeeding?

	NOT AT ALL IMPORTANT (1)	NOT VERY IMPORTANT (2)	SOMEWHAT IMPORTANT (3)	VERY IMPORTANT (4)
My baby had trouble sucking or latching on (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My baby lost interest in nursing or began to wean him or herself (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breast milk alone did not satisfy my baby (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I thought that my baby was not gaining enough weight (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had trouble getting the milk flow to start (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't have enough milk (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My nipples were sore, cracked, or bleeding (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My breasts were overfull or engorged (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breastfeeding was too painful (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Breastfeeding was too inconvenient (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wanted to be able to leave my baby for several hours at a time (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Q179 While your baby was in the NICU, did you meet with a lactation consultant?

- ☐ Yes (1)  
☐ No (2)

Answer If While your baby was in the NICU, did you meet with a lact... Yes Is Selected

Q180 Was meeting with a lactation consultant helpful for you?

	Not at all helpful (1)	Not very helpful (2)	Somewhat Helpful (3)	Very Helpful (4)
(3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Answer If While your baby was in the NICU, did you meet with a lact... No Is Selected

Q181 Would it have been helpful to meet with a lactation consultant while you were in the NICU?

- ☐ Yes (1)  
☐ No (2)

Answer If While your baby was in the NICU, did you meet with a lact... Yes Is Selected

Q119 Please share any thoughts you have on breastfeeding and your experience with your lactation consultant.

Q98 Please answer the following questions about planning for future babies in the 12 months following the delivery of your NICU baby.

Q43 In the 12 months following the birth of your NICU baby, did you do anything to keep from getting pregnant?

- ☐ No (1)  
☐ Yes (2)

Q127 Did you get pregnant before your NICU baby's first birthday?

- ☐ Yes (1)  
☐ No (2)



Answer If Are you and your husband or partner doing anything now to... No Is Selected

Q44 What were your reasons for not doing anything to keep from getting pregnant? Please check all that apply.

- ☐ I was not having sex (1)
- ☐ I wanted to get pregnant (2)
- ☐ I did not want to use birth control (3)
- ☐ I was worried about side effects from birth control (4)
- ☐ My partner did not want to use anything (5)
- ☐ I had problems getting birth control when I need it (6)
- ☐ I became pregnant during the 12 months following the delivery of my NICU baby. (7)
- ☐ Other, please specify: (8) \_\_\_\_\_

Answer If Are you and your husband or partner doing anything now to... Yes Is Selected

Q45 Which methods of birth control did you use during the 12 months following the delivery of your NICU baby? Please check all that apply.

- ☐ Tubes tied or blocked (female sterilization) (1)
- ☐ Vasectomy (male sterilization) (2)
- ☐ Birth Control Pills, please specify which: (3)
- ☐ Condoms (4)
- ☐ Diaphragm or cervical cap (5)
- ☐ Rhythm method/ Periodic abstinence (6)
- ☐ LAM (Lactational Amenorrhea Method, or no period while nursing) (7)
- ☐ Depo shot (8)
- ☐ Vaginal Ring (NuvaRing) (9)
- ☐ Patch (10)
- ☐ Implants (Implanon, Nexplanon) (11)
- ☐ Mirena (12)
- ☐ Copper T / Paraguard (13)
- ☐ Withdrawal (14)
- ☐ Not having sex (abstinence) (15)
- ☐ Other, please specify (16)

Answer If Are you and your husband or partner doing anything now to... Yes Is Selected

Q46 How many weeks after giving birth did you begin to use a birth control method?

Q5 Please indicate how satisfied you were with your birth control method:

- ☐ Very Dissatisfied (1)
- ☐ Somewhat Dissatisfied (2)
- ☐ Neutral (3)
- ☐ SomewhatSatisfied (4)
- ☐ Very Satisfied (5)

Q47 Do you plan on having or adopting any more children at any time in your future?

Please check all that apply.

- ☐ Yes, I would like to give birth to another child. (1)
- ☐ Not sure (2)
- ☐ No, I am not planning on giving birth to another child or adopting a child. (3)
- ☐ Yes, I would like to adopt a child. (4)

Answer If Do you plan to have any more children at any time in your... Yes Is Selected

Q48 When would you like to get pregnant again?

- ☐ Immediately (1)
- ☐ Less than 6 months (2)
- ☐ 6 months to one year (3)
- ☐ One year to two years (4)
- ☐ More than 2 years from now (5)

Q115 We are interested in creating programs for mothers who have a baby (or babies) in the NICU.

Q50 Did you have any of the following services while your baby was in the NICU?

	Yes (1)	No (2)
Childcare for my older children (1)	<input type="radio"/>	<input type="radio"/>
Transportation between my home and the hospital (2)	<input type="radio"/>	<input type="radio"/>
Parking Vouchers (3)	<input type="radio"/>	<input type="radio"/>
A support person coming to my home (4)	<input type="radio"/>	<input type="radio"/>

Q121 How helpful was it or would it be to have the following services while you were participating in a program for NICU parents?

	Not at all helpful (1)	Not very helpful (2)	Somewhat helpful (3)	Very helpful (4)
Childcare for my older children (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation between my home and the hospital (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parking Vouchers (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A support person coming to my home (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q51 How helpful would a support program for NICU families be at the following times?

	Not at all helpful (1)	Not very helpful (2)	Somewhat helpful (3)	Very helpful (4)
In the week after my baby was born (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Throughout my baby's NICU stay (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In the week before my baby came home from the NICU (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After my baby came home (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q49 How helpful would you have found the following programs while you had a baby in the NICU?

	Not at all helpful (1)	Not very helpful (2)	Somewhat helpful (3)	Very helpful (4)
A program to help teach me to read my new baby's cues (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A counseling session to help me process my birth experience (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A health care provider who could provide medical care for me (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A social worker who was available to offer me support and advice over the phone (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A parent-buddy program matching new NICU parents with more experienced NICU parents for support (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
An online forum to interact with other NICU parents (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q69 Please tell us what was positive about your NICU experience.

Q70 Please tell us about what could have improved your NICU experience.

Q71 If you are interested in sharing more about your NICU experience, please contact Anna Dean at [akdean@live.unc.edu](mailto:akdean@live.unc.edu) or by calling 919-843-7865 to set up a phone interview.

Q178 Thank you for taking the time to complete this survey. The information you shared is very helpful to us as we seek to improve the NICU experience for other mothers. If you have any questions about this survey, please contact Anna Dean at [akdean@live.unc.edu](mailto:akdean@live.unc.edu) or by phone at 919- 843-7865 or Dr. Alison Stuebe at [alison\\_stuebe@med.unc.edu](mailto:alison_stuebe@med.unc.edu). If you would like more information on finding postpartum support services in your country please visit Postpartum Support International: <http://www.postpartum.net/>. For more information on postpartum depression, please visit: [http://www.med.unc.edu/psych/wmd/mood-disorders/perinatal#md\\_postpartum](http://www.med.unc.edu/psych/wmd/mood-disorders/perinatal#md_postpartum). For more information on Women's Health, please visit the American College of Obstetricians and Gynecologists webpage: [www.acog.org](http://www.acog.org) or the National Women's Health Information Center: <http://www.womenshealth.gov/>. For more information on Pregnancy and Childbirth, please visit the March of Dimes: <http://www.marchofdimes.com/>.

## Appendix B: Parental Stressor Scale: Neonatal Intensive Care Unit (PSS: NICU)

Below is a list of items that might describe the way your BABY LOOKS AND BEHAVES while you are/were visiting in the NICU as well as some of the TREATMENTS that you have seen done to your baby. Not all babies have these experiences or look this way, so choose the "not applicable" 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.

	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful	× Not Applicable
Tubes and equipment on or near my baby	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
Bruises, cuts or incisions on my baby	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
The unusual color of my baby (for example, looking pale or yellow jaundiced)	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
My baby's unusual or abnormal breathing patterns	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
The small size of my baby	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful	× Not Applicable
The wrinkled appearance of my baby	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
Having a machine (respirator) breathe for my baby	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
Seeing needles and tubes put in my baby	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
My baby being fed by an intravenous line or tube	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
When my baby seemed to be in pain	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful	× Not Applicable
When my baby looked sad	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
The limp and weak appearance of my baby	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
Jerky or restless movements of my baby	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
My baby not being able to cry like other babies	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>

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/ were for you. Choose the option that best represents your level of stress while in the NICU.

	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful	× Not Applicable
The presence of monitors and equipment	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>

	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful	× Not Applicable
The constant noises of monitors and equipment	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
The sudden noises of monitor alarms	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
The other sick babies in the room	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
The large number of people working in the unit	<input type="radio"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="radio"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>

How do you feel about your own RELATIONSHIP with the baby and your PARENTAL ROLE. If you have experienced the following situations or feelings, indicate how stressed you have been by them by clicking the circle. Again, choose Not Applicable if you did not experience the item.

	Not at all stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful	× Not Applicable
Being separated from my baby	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
Not feeding my baby myself	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
Not being able to care for my baby myself (for example, diapering, bathing)	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
Not being able to hold my baby when I want	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
Feeling helpless and unable to protect my baby from pain and painful procedures	<input type="radio"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="radio"/>	<input type="checkbox"/> <input type="radio"/>	<input type="checkbox"/>
Feeling helpless about how to help my baby during this time	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>
Not having time alone with my baby	<input type="checkbox"/> <input type="radio"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>	<input type="radio"/> <input type="checkbox"/>

## **Appendix C: Modified Perinatal Post-Traumatic Stress Disorder (PTSD) Questionnaire (PPQ)**

Scored on Likert Scale: 0= not at all,' 1='once or twice,', 2= 'sometimes,' 4 'often, but less than 1 month' and 5='often, for more than a month.'

- (1) Did you have bad dreams of giving birth or of your baby's hospital stay?
- (2) Did you have upsetting memories of giving birth or of your baby's hospital stay?
- (3) Did you have any sudden feelings as though your baby's birth was happening again?
- (4) Did you try to avoid thinking about childbirth or your baby's hospital stay?
- (5) Did you avoid doing things that might bring up feelings you had about childbirth or your baby's hospital stay (e.g., not watching a TV show about babies)?
- (6) Were you unable to remember parts of your baby's hospital stay?
- (7) Did you lose interest in doing things you usually do (e.g., did you lose interest in your work or family)?
- (8) Did you feel alone and removed from other people (e.g., did you feel like no one understood you)?
- (9) Did it become more difficult for you to feel tenderness or love with others?
- (10) Did you have unusual difficulty falling asleep or staying asleep?
- (11) Were you more irritable or angry with others than usual?
- (12) Did you have greater difficulties concentrating than before you gave birth?
- (13) Did you feel more jumpy (e.g., did you feel more sensitive to noise, or more easily startled)?
- (14) Did you feel more guilt about the childbirth than you felt you should have felt?