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The Course Of Acute Stress Disorder And Post Traumatic Stress Disorder In Parents With Infants In The Neonatal Intensive Care Unit

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THE COURSE OF ACUTE STRESS DISORDER AND POST TRAUMATIC STRESS
DISORDER IN PARENTS WITH INFANTS IN THE NICU WITH OR WITHOUT
GENETIC ANOMALIES

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THE COURSE OF ACUTE STRESS DISORDER AND POST TRAUMATIC STRESS DISORDER IN PARENTS WITH
INFANTS IN THE NEONATAL INTENSIVE CARE UNIT

A

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Presented to the Faculty of

The University of Texas

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for the Degree of

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by

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Houston, Texas

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THE COURSE OF ACUTE STRESS DISORDER AND POST TRAUMATIC STRESS
DISORDER IN PARENTS WITH INFANTS IN THE NEONATAL INTENSIVE CARE UNIT

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NICU parents have up to a 60% chance to develop acute stress disorder (ASD) and/or post-traumatic stress disorder (PTSD) during or after their baby's NICU stay. Emotional and demographic factors contributing to ASD/PTSD have been previously identified. Although support factors desired by NICU parents have been described, it has not yet been determined how the presence or absence of these desired support factors may impact the development of ASD/PTSD. English and Spanish speaking parents over the age of 18 were eligible to participate in a survey that assessed stress, coping and support in the NICU. Participants also completed a validated PTSD checklist tool for the DSM-5 (PCL-5). Wilcoxon rank-sum test and Mann-Whitney U were used to analyze categorical data between groups. In total, 31% of parents qualified with high-risk scores on the PCL-5 indicating a provisional diagnosis of ASD or PTSD. Education level of parent and reason for NICU stay including birth defects and genetic conditions, were not found to be associated with increased PTSD risk. Factors that were found to be associated with increased PTSD risk include desire for an in-hospital support group, desire for increased time with the baby's care team, and desire for education on how to care for their baby after the NICU. Parents also indicated reasons for their fears, best and hardest days in the NICU. Parents who identified a fear of uncertainty were more likely to have lower PCL-5 scores, indicating a potential protective factor for parents when uncertainty is recognized and accepted. Findings suggest that NICUs should consider a multidisciplinary approach to communicate with families.

And, while all parents should be offered support in the NICU regardless of medical concerns their baby is experiencing, anticipatory guidance about future plans for the baby may be of substantial benefit to parents.

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INTRODUCTION

When a newborn needs critical medical attention, parents are thrust into a dizzying and confusing journey that often begins in the neonatal intensive care unit (NICU). Indications for specialized care and a resulting NICU stay may include but are not limited to prematurity, birth defects and/or genetic conditions. Even though parents recognize and appreciate the lifesaving medical care provided in the NICU, it is frequently a scary and worrisome experience for them. In the aftermath, it is common for parents of children in the NICU to develop mental health symptoms, including depression and anxiety disorders (Aftyka et al., 2017). Not surprisingly, there is a high incidence of a specific anxiety disorder known as post-traumatic stress disorder (PTSD) among NICU parents.

It has been previously reported that approximately half of parents (60% in mothers and 47% in fathers) develop PTSD during or after their child's NICU stay (Shaw et al., 2013, Aftyka et al., 2017). Identified risk factors for the development of PTSD in mothers include previous miscarriages, maternal chronic disease such as asthma or epilepsy, emotional disengagement, and increased education levels (Shaw et al., 2013). Although NICU fathers are less studied than mothers, there is a positive association between fathers developing PTSD symptoms when his child has a higher one-minute neonate APGAR score, his child does not have congenital anomalies and if his partner has PTSD. These associations suggest that a contributing factor to fathers developing PTSD may be a lack of mental preparedness for their child's NICU stay while confounding medical history stressors appear to contribute to mothers' risks.

In a more recent study by Shaw et al. (2013), parental coping mechanisms were the only significant contributory factors of parental PTSD. They found that mothers of premature infants who utilized positive coping strategies such as mobilizing social support were less likely to

experience PTSD. They also found that mothers who mentally and emotionally disengaged had increased risks to develop PTSD (Shaw et al., 2013).

Although both NICU mothers and fathers are at an increased risk to develop PTSD when they have a child in the NICU, fathers have been found to show symptoms of acute stress less commonly when compared to mothers. Acute stress disorder (ASD) is characterized by post-traumatic stress symptoms between three days and one-month post-trauma. If symptoms exceed one month, ASD becomes classified as PTSD. Thus, ASD is a risk factor for developing PTSD (Bryant et al., 2016). Studies based in the pediatric intensive care unit (PICU) parent population have shown a significant proportion (30%) of parents have a formal ASD diagnosis after a child's admission (Nelson et al., 2019). Factors found to elevate this risk of developing ASD are past psychiatric disorders, prior trauma, greater trauma severity, avoidant coping, high neuroticism, and being female (Bryant et al., 2016).

Parents have been shown to benefit from open communication throughout the duration of their infant's stay in the NICU (Miquel-Verges et al. 2009 and Berman et al, 2019). Miquel-Verges et al. went on to find that parents perceive the most important aspects of their child's care to be parental preparation, knowledgeable physicians, caring providers, allowing hope, and time. The Berman group also found that parents need emotional support and resources in the form of training, financial help and emotional help (Berman et al., 2019). Some mothers valued preparation and desired to know all possible scenarios that could be expected and the management plan for their infant while others coped better with minimal information (Lalor JG et al., 2008). These findings suggest that the preferred level of information varies between individuals, supporting that consultation with each family should be tailored and patient-centered. A NICU consult, including a tour of the NICU, consistently reduced mothers' anxiety about their child's NICU stay (Miquel-Verges et al., 2009). Specifically, a tour was helpful to

better understand not only what the NICU looks like, but it was also found to be helpful and reassuring to witness staff caring for patients.

NICU parents are at an increased risk to develop ASD and/or PTSD during or after their child's NICU stay. While these parents desired varied support and information from their child's care team, it has not yet been determined how the presence or absence of these desired support factors may impact the development of ASD/PTSD. In addition, available studies mainly focused on English-speaking NICU mothers. Identifying contributing factors to the course of ASD and PTSD in a diverse NICU parent population is important for long term outcomes for families as many parents experience PTSD symptoms a year or more after their NICU experience. This study aimed to describe the course of ASD and PTSD in a diverse NICU parent population, and to identify factors that may contribute to this course. Additionally, this study aimed to identify patient experiences with prenatal and pediatric genetic counselors and to determine whether these interactions and/or underlying genetic conditions themselves impact parent PTSD course.

MATERIALS AND METHODS

Participants:

Mothers and fathers of infants hospitalized in the Children's Memorial Hermann Hospital (CMHH) NICU at the time of initial recruitment were asked to participate in a survey examining stress, coping, and support experienced while in the NICU. Parents met inclusion criteria if they were English or Spanish speaking and 18 years or older. This study was approved by the institutional review board of the UTHealth Graduate School of Biomedical Sciences, and Memorial Hermann Hospital (IRB Number: HSC-GSBS-19-0553.)

Measures:

The PTSD checklist for the DSM-5 (PCL-5) was used to assess acute stress symptoms. The PCL-5 is a 20 item self-reported questionnaire which is widely used as a DSM-5correspondent measure of PTSD symptoms. The PCL-5 has demonstrated reliability and validity to measure symptoms of PTSD. Participants rated their experiences with different symptoms of PTSD and indicate on a scale from 0 (Not at all) to 4 (extremely) the level of severity and burden of each symptom. The PCL-5 is tallied by summing the score for each of the 20 questions (range 0-80). A score of 31 or higher is considered a reasonable provisional diagnosis of PTSD.

An accompanying survey was created to assess parental NICU experience including targeted questions assessing coping mechanisms and support systems. In addition, the survey assessed parent satisfaction with genetic counseling and neonatology consults when applicable. Follow-up surveys included questions about experience over the intervening month and included the PCL-5 scale to evaluate symptoms of PTSD over time.

Design:

The participants completed an initial survey at the time of recruitment. Participants had the option of taking the survey electronically via Qualtrics or on paper, in English or in Spanish. Responses to the paper surveys were entered into the Qualtrics system by the PI following recruitment. The initial survey contained the PCL-5 in addition to questions specific to the NICU experience. Participants were given the option to receive an invitation to participate in a follow-up survey 30 days after completing their initial survey. If the follow-up survey was completed, they were then invited to receive an invitation to participate in a third and final survey which was sent after an additional 30 days. The follow-up surveys additionally assessed parental coping and satisfaction along with PTSD using the PCL-5. Since the PCL-5 is a tool that can track the course of PTSD over time, the follow-up measure provided information about PTSD signs in a

parent if their baby had been in the NICU fewer than 30 days at the time they took the initial survey.

Due to the possibility that individuals at risk for developing PTSD would be identified in this study, web links and contact information for support resources were provided. Participants were also given an opportunity to share their name and physician information so that a request for referral to a psychologist could be made on their behalf if they did not feel comfortable reaching out on their own but desired counseling.

Recruitment of participants was both active and passive. Active recruitment involved the PI visiting the NICU throughout the study period to share information about the study with NICU mothers and fathers. In addition, the genetic counselor typically involved in NICU consults invited parents to participate after meeting with a family who met inclusion criteria. A QR code invitation to the survey was posted on the reception desk of the NICU entrance for parents to scan and participate for passive recruitment. As an incentive to participate, there was a weekly drawing for hospital parking validation given to a parent chosen by a randomizer who completed a survey that week. In addition, a parking validation was provided to all participants of follow-up surveys who still had a baby in the NICU.

Statistical analysis:

Data obtained from the surveys was entered into a secure database. Depending on timing of initial recruitment (more/less than 30 days), PCL-5 scores were categorized into risk for acute stress or post-traumatic stress. STATA version 13.1 was used for data analysis. Categorical variables were reported as frequencies and percentages. Wilcoxon rank-sum test and Mann-Whitney U test were used to analyze categorical data between different groups. Regression analysis was also used to determine relationships between variables.

RESULTS

Demographics:

A total of 57 initial surveys were completed by mothers or fathers of babies in the Children's Memorial Hermann Hospital NICU. One survey was excluded because the participant indicated that they were neither a mother nor a father in the NICU. Two participants completed the survey twice, so their first surveys were counted in data collection. Please see Figure 1 for recruitment information.

A total of 42 mothers and 12 fathers participated in the initial survey. Surveys were completed in English (89%) and Spanish (11%). Most participants were Catholic or Christian (69%). Most participants have at least some college education (61%). About half of parents were employed full time (46%). Almost half of participants (44%) reported having private insurance, and about one third reported having public insurance (35%). Please see Table 1 for additional participant demographics.

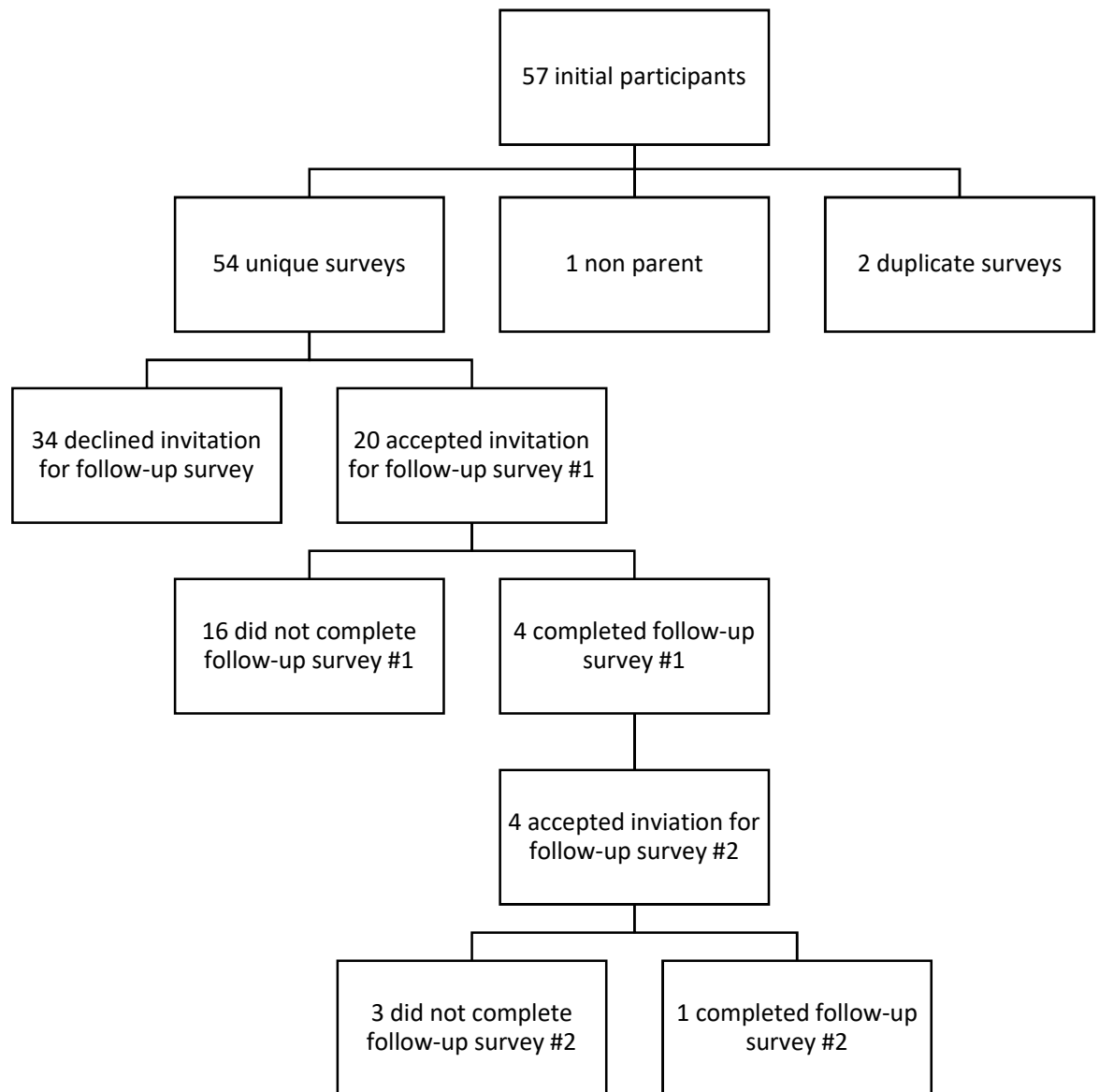


Figure 1

| Table 1 Demographic information for initial survey respondents (N=54) | | | |
|--|---------------------------|--------------|--|
| Category | | N (%) | |
| | | | |
| Age (18-44) | | | |
| | Median = 32 | | |
| | Not answered, n = 12 | | |
| | | | |
| | Mothers | 42 (76) | |
| | Fathers | 12 (22) | |
| | | | |
| Days NICU (1-326) | | | |
| | Median = 26 | | |
| | Mean = 48 | | |
| | | | |
| Language | | | |
| | English | 48 (89) | |
| | Spanish | 6 (11) | |
| | | | |
| Education | | | |
| | Less than High school | 2 (3.7) | |
| | High school graduate/ GED | 10 (18.5) | |
| | Some college | 11 (20.4) | |
| | College Degree | 13 (24.0) | |
| | Postgraduate degree | 9 (16.7) | |
| | Not answered | 9 (16.7) | |
| | | | |
| Religion | | | |
| | Catholic | 19 (35.2) | |
| | Christian (All other) | 18 (33.3) | |
| | Buddhist | 2 (3.7) | |
| | Muslim/Islam | 1 (1.9) | |
| | Agnostic | 1 (1.9) | |
| | Other | 3 (5.6) | |
| | Not answered | 10 (18.5) | |
| | | | |
| Employment Status | | | |
| | Employed full time | 25 (46.3) | |
| | Employed part time | 3 (5.6) | |
| | Unemployed | 5 (9.3) | |
| | Student | 2 (3.7) | |
| | Stay at home parent | 8 (14.8) | |

| | | | |
|--|--------------------------------|-----------|--|
| | Other | 1 (1.9) | |
| | Not answered | 10 (18.5) | |
| | | | |
| | Annual Household Income | | |
| | Less than \$19,999 | 8 (14.8) | |
| | \$20,000 - \$39,999 | 7 (13.0) | |
| | \$40,000 - \$59,999 | 3 (5.6) | |
| | \$60,000 - \$79,999 | 3 (5.6) | |
| | \$80,000 - \$99,999 | 3 (5.6) | |
| | More than \$100,000 | 8 (14.8) | |
| | Prefer not to answer | 12 (22.2) | |
| | Not answered | 10 (18.5) | |
| | | | |
| | Health Insurance | | |
| | Private | 24 (44.4) | |
| | Public | 19 (35.2) | |
| | Not Answered | 11 (20.4) | |

PCL-scores:

A total of 46 parents participated in the PTSD checklist for the DSM-5 (PCL-5). The range of scores were 0-80. The median PCL-5 score for fathers was 10 (n=9) and for mothers was 18 (n=38). About one third of parents (31%) (14 mothers, 3 fathers) showed probable ASD/PTSD based on their PCL-5 scores of 31 or higher. There were not significant differences in scores for moms and dads between parents who took surveys in English or Spanish, however all Spanish speaking participants had PCL-5 scores below 31. Of the six surveys collected in Spanish, four were completed separately by both parents of two babies; these four surveys represent two family units, not four. Of the 46 surveys completed in English, at least two were completed separately by both parents of one set of twins; these two surveys represent one family unit, not 2.

Reason for NICU stay:

The NICU stay was a surprise for most families as only 39% of parents were expecting their baby to be in the NICU. About a quarter (22%) of parents had been in the NICU before their baby was born with one individual specifying that it was to take a tour of the NICU while pregnant. Of the twelve parents who had been in the NICU before, seven had a previous child in the NICU. Expecting their baby to be in the NICU and having a previous child in the NICU did not impact PCL-5 scores ($p=0.6035$, $p=0.1191$ respectively).

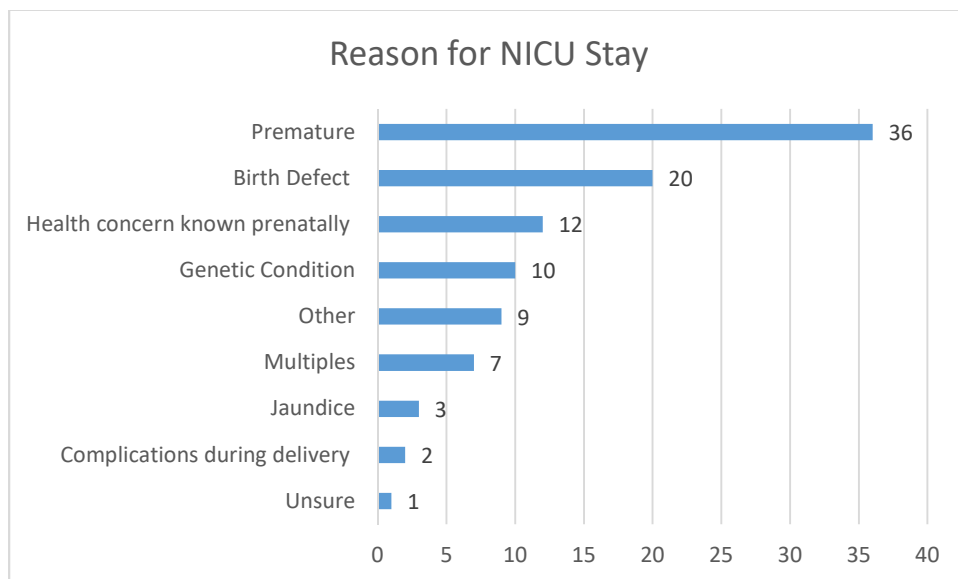


Figure 2

Most participants indicated that their baby was in the NICU due to prematurity ($n=36$). A total of 20 parents (37%) indicated that their baby was in the NICU due to a birth defect. See Table 2 for a list of birth defects reported by parents. A total of 10 parents (18.5%) designated that their baby was in the NICU due to a genetic condition. Genetic conditions reported by parents were triploidy ($n=2$), “cromosoma 11” ($n=2$), a “chromosome condition” ($n=1$), CDH ($n=1$), and unspecified ($n=4$). Of note, the parents who child had a “cromosoma 11” condition represent both a mother and father of the same infant. Twelve parents selected that the reason their baby was in the NICU was due to health concerns

known prenatally. PCL-5 scores were not significantly affected by the reported reason for NICU stay, type of genetic condition or type of birth defect ($p=0.4716$, $p=0.6942$, respectively).

| Table 2 Reported Birth Defects | |
|---------------------------------------|---|
| CDH | 3 |
| Heart Defect | 3 |
| Cleft Palate | 2 |
| Spina Bifida | 1 |
| Duodenal Atresia | 1 |
| Esophageal Atresia & Horseshoe kidney | 1 |
| Pulmonary Stenosis | 1 |
| PDA | 4 |
| Not Specified | 4 |

Almost half of parents reported that their baby either already had a surgery or was expected to have a surgery in the future ($n=24$). There was not an association between a baby needing surgery and a parent's PCL-5 score. Most parents reported their baby needed an IV ($n=38$) and/or a feeding tube ($n=34$). Parents whose babies required a feeding tube were more likely to have higher PCL-5 scores than other parents ($p=0.0057$). (figure 3).

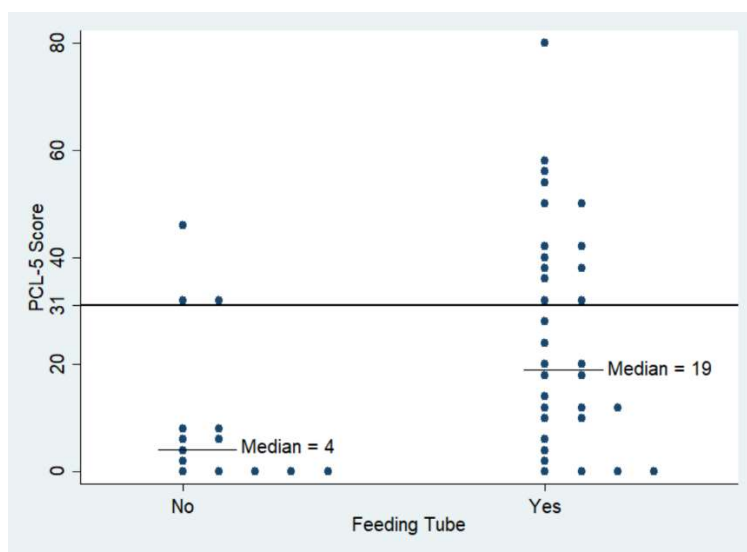


Figure 3

Resources and support:

Healthcare providers

Nine parents with a baby with a birth defect, and three parents with a baby with a genetic condition and/or birth defect report speaking with a genetic counselor during pregnancy specifically due to their baby's diagnosis. Four parents with a baby with a birth defect and one parent with a baby with a genetic condition report meeting with a neonatologist prior to delivery. Responding to a five part Likert scale from strongly disagree to strongly agree, parents who met with a prenatal genetic counselor during pregnancy about their baby's birth defect or genetic condition selected positive scales for their prenatal genetic counselor. Participants strongly agreed that they felt supported and that they recommend prenatal genetic counseling. Two-thirds of answering participants felt like their prenatal genetic counselor prepared them for their time in the NICU (Figure 4). Parents who met with a neonatologist prenatally overall would recommend meeting with a neonatologist prior to delivery to other parents. They agreed that neonatologists made them feel supported before delivery, helped them understand their baby's medical concerns and answered all of their questions (Figure 5). Participants who met with a pediatric genetic counselor after delivery (n=8) selected more varied answers to this Likert scale than for the neonatologist and the prenatal genetic counselor. Half of participants who saw a pediatric genetic counselor strongly agreed that it was helpful, and that they understood the information their pediatric genetic counselor discussed with them and half disagreed with these statements. Five (62% of those who met with a pediatric genetic counselor) participants felt that their pediatric genetic counselor prepared them for their experience in the NICU (Figure 6.) There were not significant relationships between PCL-5 score and having a prenatal meeting with a neonatologist or prenatal genetic counselor, or a postnatal meeting with a pediatric genetic counselor.

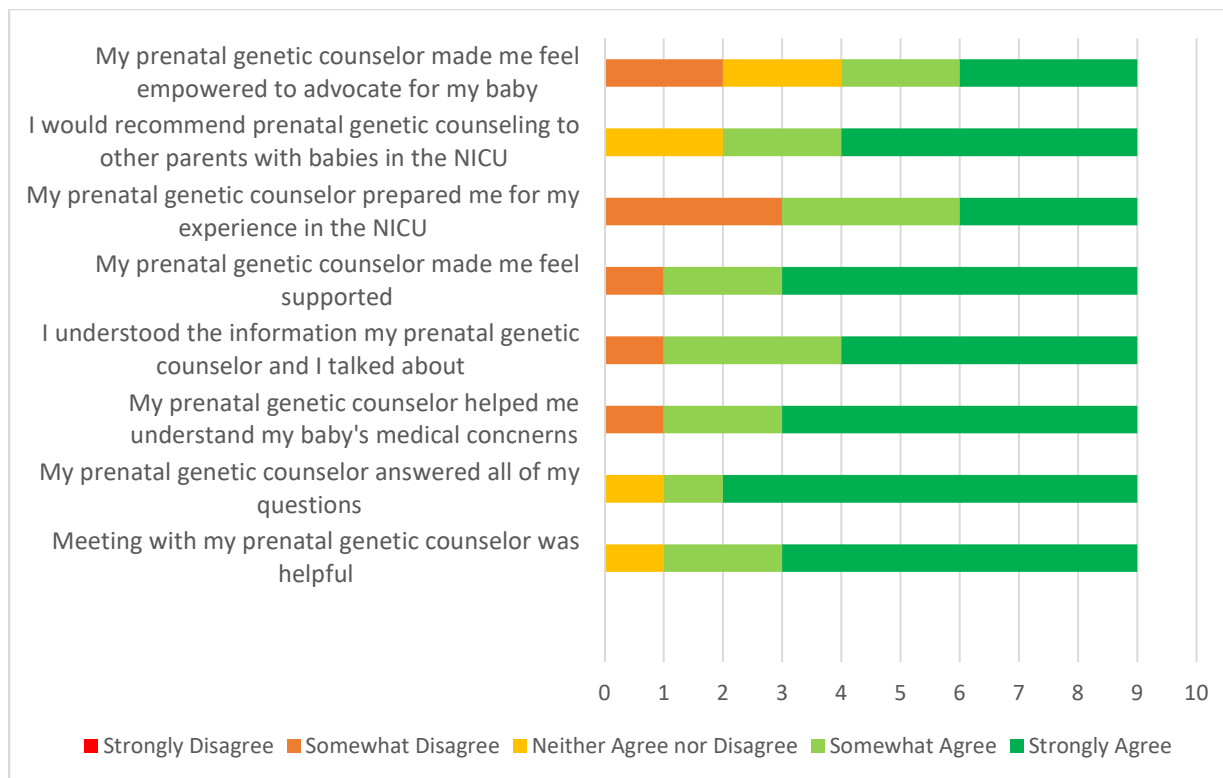


Figure 4

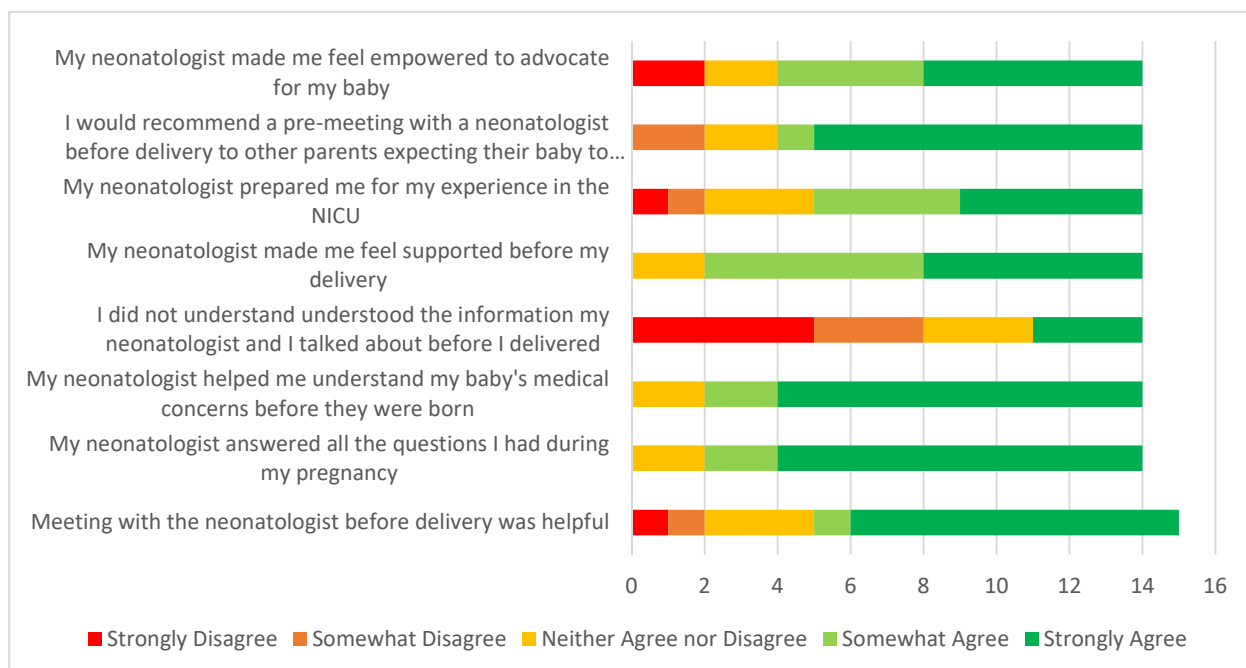


Figure 5

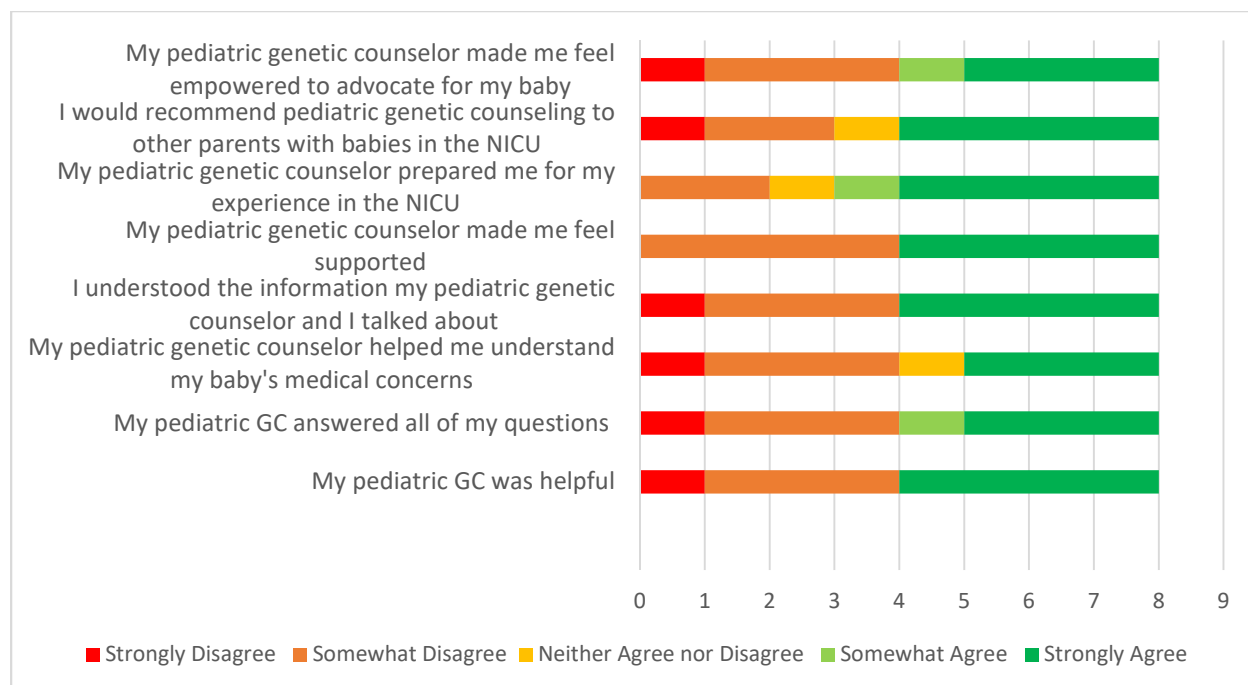


Figure 6

Emotional Support and Experiences:

Parents most commonly reported receiving emotional and mental support from family members (n=43), their partner (n=39), and their faith (n=36). Most parents participated in holding their baby (n=42), care activities like bathing or changing their baby's diaper (n=40), and taking pictures of their baby (n=43). Eight parents reported journaling during their time in the NICU. Parents who participated in journaling were more likely to have higher PCL-5 scores (median score = 31) than those who did not (median score =11; p=0.049) (Figure 7).

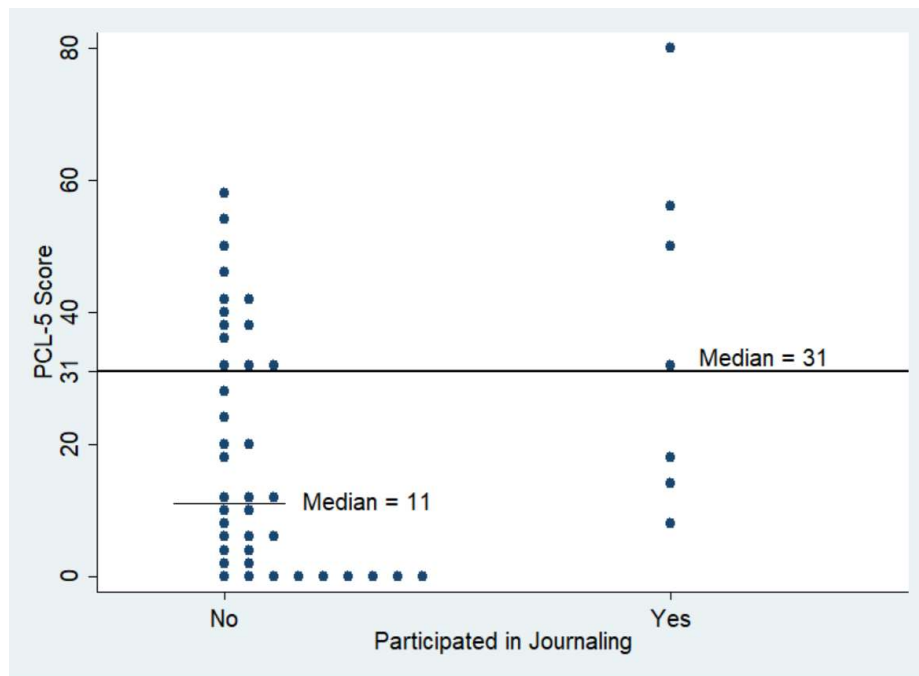


Figure 7

Half of parents reported that their own feeling of being overwhelming was the reason for their hardest day in the NICU (n=27). Parents also selected that their baby being diagnosed with a new condition (n=19) and their baby unexpectedly getting worse as common reasons for their hardest day in the NICU (n=18). Although selected less commonly, parents who selected that their baby had surgery (n=14) and that their baby died (n=2) reported that those factors were the most impactful in contributing to their hardest day in the NICU (figure 9). Additionally, parents who selected their baby having surgery as a reason for their hardest day in the NICU were more likely than other parents to have higher PCL-5 scores with a median of 29 ($p=0.0113$). Parents were most often afraid that their baby will die (n=28), and that it was the most impactful fear. Parents were most commonly afraid that their baby will be in distress (n=25) and that their baby will not get better (n=23) (figure 10). The parents who were afraid that their baby won't get better were more likely to have higher PCL-5 scores with a median score of 23 than parents who did not select that as a fear (median = 5; $p=0.0164$) (figure 8). The seven parents who indicated a fear of not knowing what to expect on any given day were more likely to have lower

PCL-5 scores with a median score of 0 than the other parents who did not select that fear (median =18.5) ($p=0.0164$).

Mothers were more likely to be afraid of not being able to see their baby enough as compared to fathers ($p=0.027$). Dads were just as likely as mothers to select that not being able to visit or hold their baby as factors for their hardest day in the NICU ($p=0.5917$).

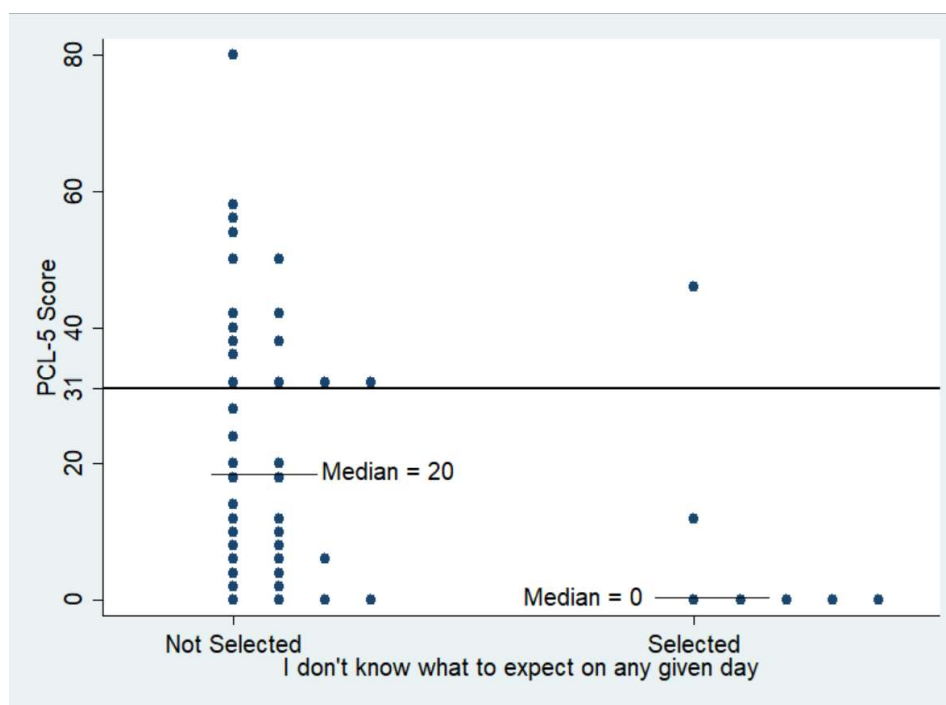


Figure 8

The most frequent and most impactful reason for the parent's best day in the NICU was their baby having a good day ($n=41$) and themselves being able to care for their baby more that day ($n=38$). It was also most impactful for parents when their baby's surgery went well ($n=14$) (figure 11). Parents who selected a reason for their best day in the NICU was their baby's procedure going well were more likely to have higher PCL-5 scores with a median score of 29 ($p=0.0138$). There were twelve parents who

selected both the reason for their hardest day in the NICU was their baby having surgery and the reason for the best day in the NICU was their baby's procedure going well.

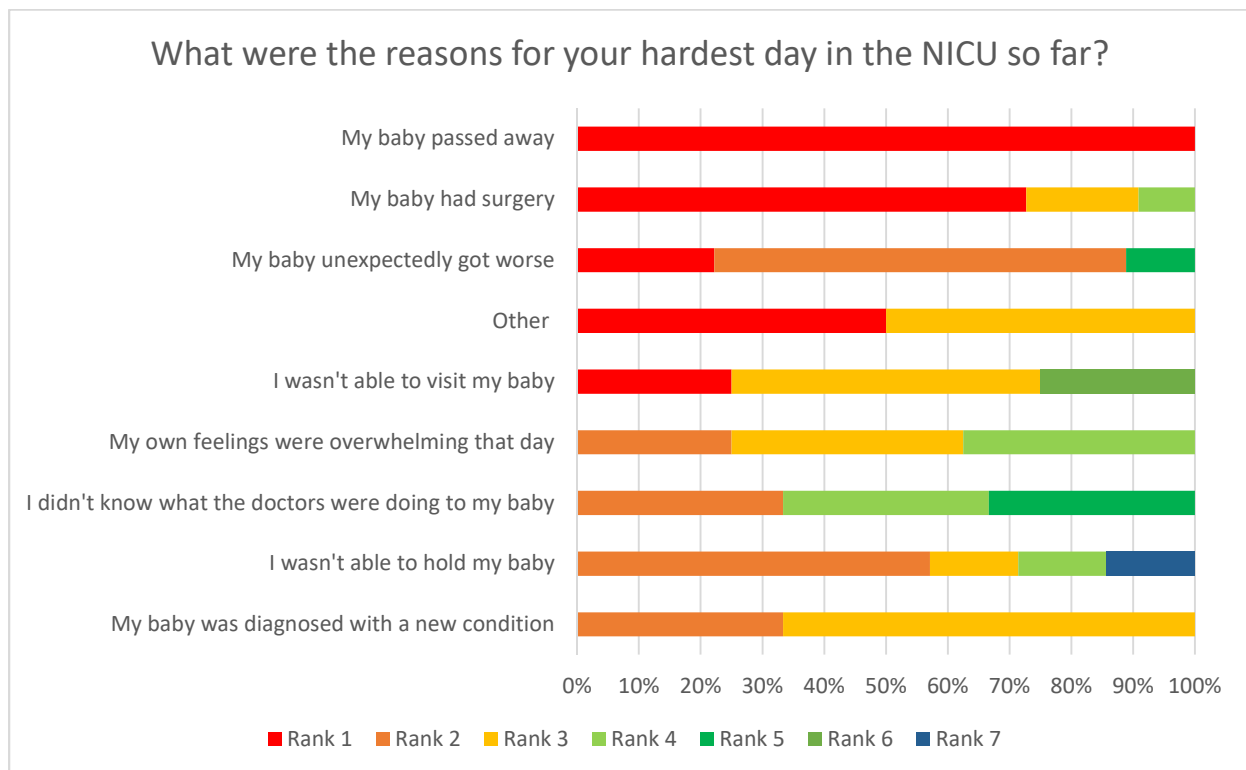


Figure 9



Figure 10

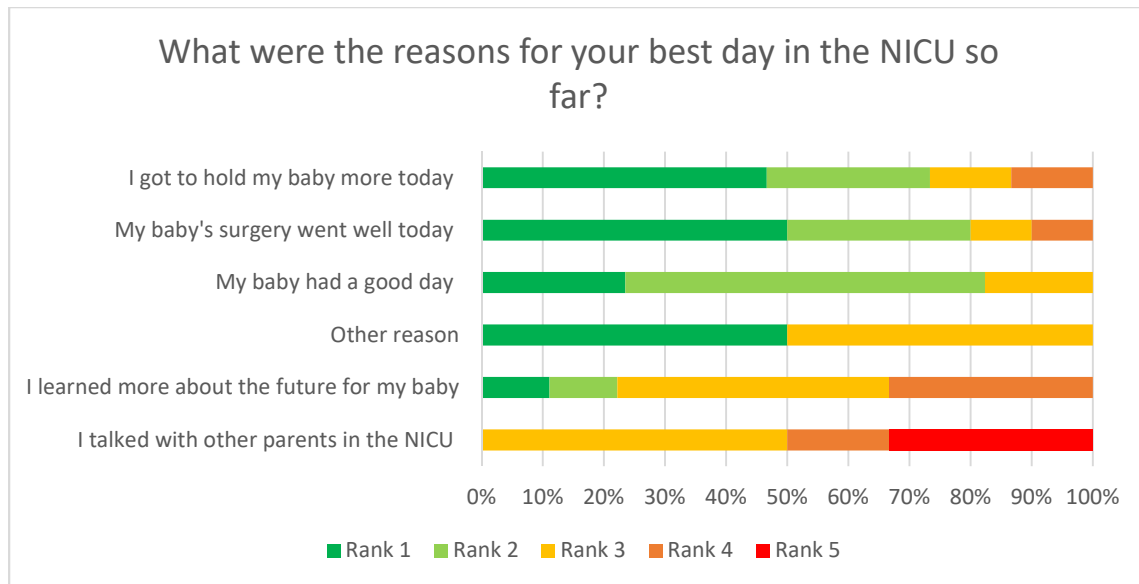


Figure 11

Resources and support parents desire:

About half of participants expressed that they wished that they knew how long their baby would need to be in the NICU (n=29) and what types of procedures their baby would need (n=23). About one-quarter of parents desired knowing more information about their baby's care team (n=15). Half of parents reported wanting more information about caring for their baby after the NICU (n=27); these parents were more likely to have higher PCL-5 scores than other parents (median = 27, median = 5.5 p=0.024) (Figure 13).

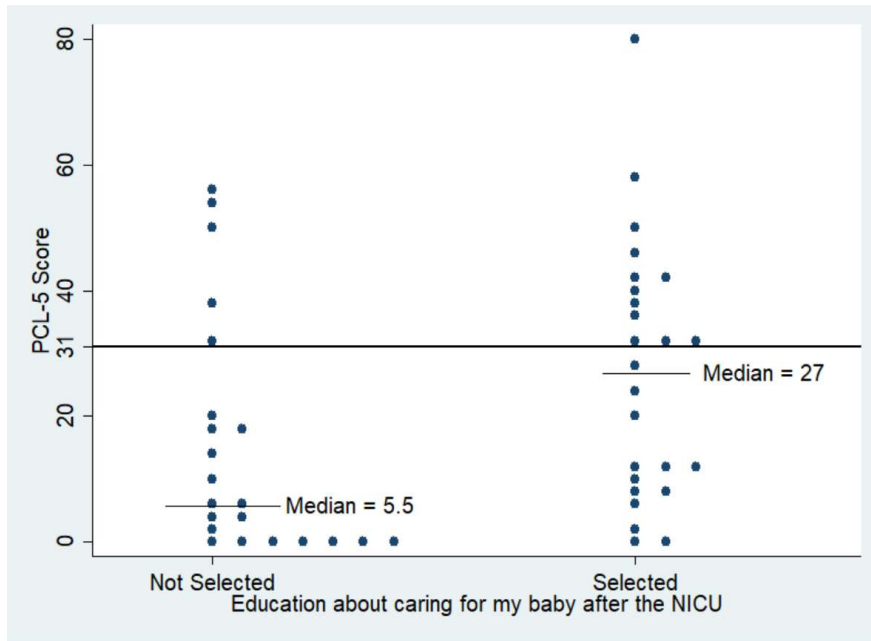


Figure 13

Over one third of parents desired more time with their baby's care team to discuss the care plans ($n=19$); these parents were more likely to have higher PCL-5 scores with a median score of 34 than parents who did not ($p=0.024$) (Figure 14).

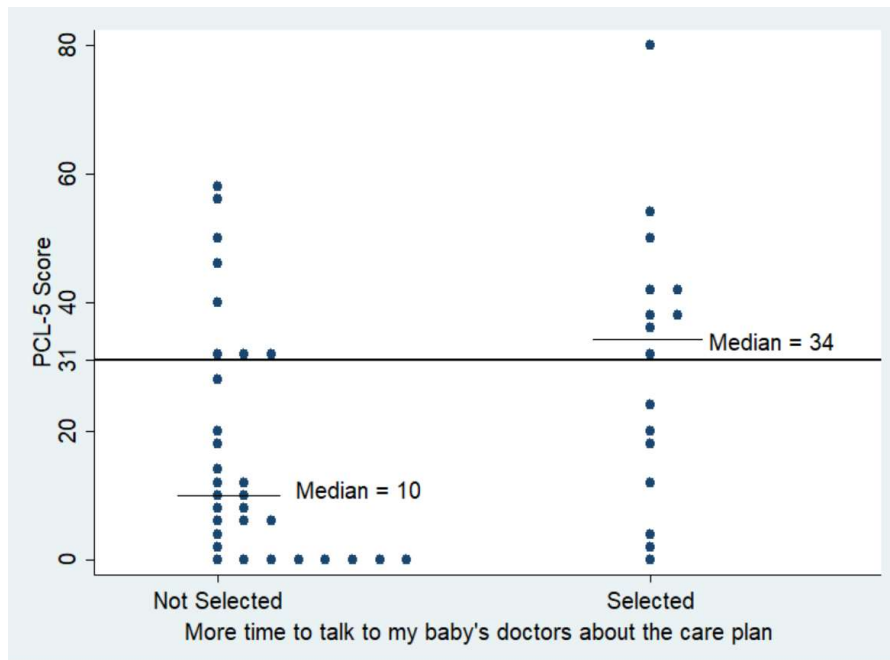


Figure 14

Additionally, about one quarter of parents desired assistance understanding the finances in the NICU (n=15). Annual income was not associated with desire for understanding the finances of the NICU ($p=0.54$), however parents with private insurance were more likely than parents with public health insurance to desire assistance with understanding the finances in the NICU ($p= 0.028$). About a quarter of parents expressed desiring a hospital support group for NICU parents (n=15), one parent specified wanting a support group option that met outside of work hours. The parents who desire an in-hospital support group are more likely to have higher PCL-5 scores, with a median score of 32 than parents who did not indicate that desire ($p=0.005$) (figure 15).

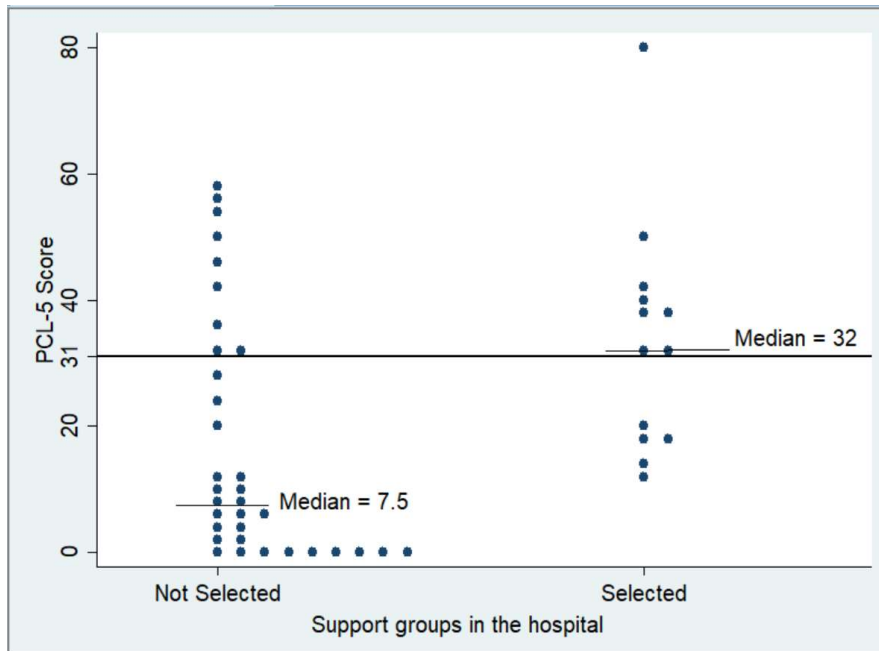


Figure 15

Follow-up:

Twenty-four parents indicated that they would like to participate in the follow-up survey. Four participants completed the follow-up survey. Of note, all parents who had a baby still in the NICU during the time of the follow-up survey have higher PCL-5 scores than for their initial survey ($p=0.2130$). One mother had an initial score of 11, and her follow up score was 33. This means that she developed a provisional diagnosis of PTSD between participating in the initial survey and the follow-up survey. Both discharged parents had lower PCL-5 scores of 0 and 3 for their follow-up survey down from 5 and 10 respectively.

The parents whose babies were discharged strongly agreed that their healthcare providers communicated with them clearly and consistently while their baby was in the NICU. Two also strongly agreed that they had access to resources and felt prepared to take care of their baby at home. Two parents indicated that they did not need more resources in the NICU. Both parents were given

information on their baby's medical condition and about how to care for their child at home. One parent indicated that the NICU stay has been extremely financially burdensome.

All four parents indicated that they would like to participate in a second follow-up survey. One parent completed the second follow-up survey. The mother who participated in the second follow-up survey indicated again that she did not desire any more resources from the NICU, and had a PCL-5 score of zero.

DISCUSSION

The current study found that about one third of participating NICU parents are at a high risk for Acute Stress Disorder (ASD) and thus Post Traumatic Stress Disorder (PTSD). This is consistent with previous studies which identified a 30-60% chance for NICU parents to develop PTSD (Shaw, 2013, Afkya et al., 2017). Previously identified factors that may contribute to the development of PTSD in NICU parents were not confirmed in the current study. Specifically, education level, and reason for NICU stay, including genetic conditions and birth defects, were not found to correlate with PTSD risk.

Despite medical reasons for their baby's NICU stay not being associated with measured parental stress, medical aspects of their NICU stay did appear to contribute. Unsurprisingly, the most commonly reported and impactful fears of NICU parents were the possibility of their babies dying or being in distress. Additionally, whether or not a baby required a feeding tube appeared to significantly affect PCL-5 scores with parents whose babies required a feeding tube having a significantly higher median score. This finding is validated by a recent study that also identified the need for a feeding tube to be a top stressor (Schechter et al., 2020). Feeding their baby is an important way that parents can contribute to the care of their baby in the hospital setting. In fact, most parents identified that a reason for their best day in the NICU was being able to hold and participate in a care activity for their baby. One parent specifically indicated that getting to bottle feed her baby was a reason for her best day in the NICU.

Independent feeding is an important step toward discharge from the NICU. Therefore, a child needing a feeding tube can additionally take away a parent's sense of control, normalcy and involvement.

Understandably, these losses may create stress for many parents.

In addition to not being able to feed their baby, Schecter et al. identified that separation from their baby and not being able to hold their baby were top stressors for NICU parents. When asked about fears in the current study, fathers were less likely than mothers to indicate a fear of not visiting their baby enough, however, both mothers and fathers report that their hardest day was due to not being able to see or hold their baby. Previous studies have identified the importance of touch in parent/baby bonding for both mothers and fathers (Fisher et al., 2018, Lindberg et al., 2008). Mothers and fathers alike are impacted when they cannot see or hold their baby.

When asked about activities that they participated in to help manage stress, parents who participate in journaling had a median PCL-5 score of 31, or high risk for PTSD. Additionally, parents who desire an in-hospital support group had a high-risk median PCL-5 score of 32. It makes sense that parents experiencing more stress desire and/or utilize more coping support than others. Somewhat surprisingly, parents who identify fear of uncertainty were found to have a lower PCL-5 score than other parents. Uncertainty may be impacting all parents, but those who are aware and accepting of the uncertainty in the NICU appear to be somewhat protected compared to those who did not identify the possibility of uncertainty in the NICU. Health care providers may consider normalizing that stress can be caused by uncertainty in the NICU. This may help manage expectations for parents, and reduce parent stress levels.

The CMHH NICU provides an education package about the NICU to all NICU parents once admitted and typically offers educational materials and tours to all parents receiving prenatal consults with neonatology who have expected NICU stays based on prenatal findings. Parents indicated in this

study that they would recommend a prenatal consult with a neonatologist. Of note, about 15% of parents reported that they had previously been in the NICU before delivery; this included parents who either had a previous child in the NICU, or who visited the NICU before delivery.

Despite parents being offered these resources, the current study identified that about one-third of all parents wish they had more time with their baby's care team during their NICU stay, half of parents desired more education for caring for their baby after the NICU, and 20% of parents desired more written information in the NICU. Parents with and without prenatal consults wish for more time with their baby's providers. Berman et al. (2019) found in a qualitative study that parents do desire clear, consistent, and ongoing communication with their baby's providers. In this study, parents who desire more time with their doctors experienced higher levels of stress as did parents who desire more education about after NICU care. However, the four parents who participated in the follow-up survey indicated that they did not desire more information for caring for their baby after the NICU. This is likely because the CMHH NICU provides preparation about caring for their baby at the time of discharge.

In general, parents desire resources about the finances of the NICU (Berman, 2019). Parents across all incomes were interested in understanding finances in the NICU. Income or insurance status did not impact PCL-5 scores, but understandably, parents who had private insurance in the current study were more likely than parents with public insurance to desire support in understanding the finances of the NICU. One mother indicated in her follow-up survey that the stay in the NICU has been extremely financially burdensome. All parents should be offered support in understanding finances of the NICU, but extra availability should be considered in hospitals with a patient population that has a higher proportion of private insurance holders.

To meet this self-identified need for communication of information with parents, NICUs may consider a multidisciplinary and anticipatory approach for communication with families. Perhaps

communicating with parents that support and education will be provided in the future could help to ease these concerns and lower parent stress. There does seem to be space for the role of genetic counselors in the NICU setting to provide additional communication with families. Parents agree that they recommend seeing a prenatal or pediatric genetic counselor during pregnancy or while in the NICU. Given the small sample size of parents who reported seeing a genetic counselor pre or postnatally, further studies should be conducted to identify the roles that genetic counselors can play in the care of NICU families. Considering the desire of parents for more education and more time with their care team, the role of the genetic counselor can play in education is promising. Given the known emotional stress the NICU can cause and that validation, normalization and anticipatory guidance may help parents adjust, consideration for a mental health provider such as a psychologist on the NICU team is warranted.

This study did have several limitations. The sample size of the study was limited, especially for the follow-up surveys, and not all questions were answered by every parent. However, this study was available to both parents, English and/or Spanish speaking individuals, in a diverse NICU. This study did not query protected health information, therefore reported diagnoses of genetic conditions, birth defects and surgeries were not confirmed; this study focuses on parent perceptions of these medical concerns. For example, a large patent ductus arteriosus was reported by some parents as a birth defect. Additionally, the PCL-5 is a self-reported measure, and not a formal diagnosis of PTSD. However, the PCL-5 is a validated tool that follows the most up to date DSM-5. The follow-up surveys for the first 10 participants were not sent right at the 30-day follow-up time period due to technical complications. This was corrected for the remaining parents who elected to receive follow-up surveys. This study also did not evaluate parents who weren't able to visit their babies in the NICU or who did not visit at the time of PI visitation because most parent participants were actively recruited. Additionally, we recognize that other family members including adoptive parents, grandparents, aunts/uncles, and siblings may also

experience stress from the NICU. Future studies should consider expanding to include these additional loved ones.

Overall, several studies, including this study indicate that at least one third of parents with babies in the NICU are at risk to develop PTSD. The risk for parents to develop acute or post-traumatic stress should not be assumed based on severity of the baby's medical indication because this study indicated that parent perception of the reason for their baby's NICU stay was not associated with parent PCL- 5 scores. Therefore, resources should be provided to all parents to educate and help them cope with their NICU stay. Although most parents report access to emotional and mental support through family and faith, they still desire additional support resources. All NICUs should also consider forming an in-hospital support group as another option for NICU parents to process with variable meeting times to allow attendance of any and all interested parents/family members. Recognizing the prevalent risk for trauma among parents that is demonstrated by this study, future research might turn to the best means of communicating resources that might mitigate this trauma. Specifically, studies might investigate parent perceptions of education material offered in the NICU in order to create a trauma-informed program that is most beneficial to help parents.

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