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Uncertainty and Perinatal Posttraumatic Stress Disorder in the Neonatal Intensive Care Unit

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Abstract

Parents of infants in the Neonatal Intensive Care Unit (NICU) are at increased risk of developing perinatal post-traumatic stress disorder (PPTSD), a mental health condition known to interfere with healthy parental and infant attachment. Feelings of uncertainty about illness have been theorized as an antecedent to post-traumatic stress, however the relationship has not been explored in parents of infants requiring care in the NICU. The purpose of this prospective study was to explore parental uncertainty during and after NICU discharge and the relationship between uncertainty and PPTSD. The sample consisted of 319 parents during NICU hospitalization and 245 parents at three months post-discharge. Parents who screened positive for PPTSD three months after hospital discharge reported more uncertainty both while in the NICU and three months after hospital discharge ($p < 0.001$). In parents with a personal or family history of mental illness, the moderated/mediating structural probit analysis showed no direct or indirect effect of uncertainty during hospitalization or at three months after hospital discharge on screening positive for PPTSD. In parents who did not report personal or family history of mental illness, uncertainty at three months after hospital discharge had a direct effect ($b=0.678$, $p<0.001$) and indirect mediating effect ($b=0.276$, $p<0.001$) on screening positive for PPTSD. The results provide actionable implications for mental health and NICU providers: (1) routine screening for uncertainty and risk factors including previous personal and family history of mental illness, and (2) the development of NICU follow-up support services to mitigate risk for PPTSD.

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Keywords

Perinatal post-traumatic stress disorder; parent uncertainty; NICU; PTSD

Parents of infants requiring hospitalization in the Neonatal Intensive Care Unit (NICU) often report high levels of stress, anxiety, and depression (Roque et al., 2017). Their experience is often underscored by feelings of uncertainty about their infant's illness. Low socioeconomic status and decreased support have been identified as increasing risk for uncertainty in parents of infants in the NICU (Bolívar Montes & Montalvo Prieto, 2016). Uncertainty about illness has been theorized to be an antecedent to traumatic stress in parents of sick children (Santacroce, 2003). The uncertainty that parents of sick infants experience is unique as compared to that experienced by parents of older children (Malin & Johnson, 2019). This uncertainty is uniquely associated with both the immediate and long-term prognosis as well as the complexities of illness and care management needs for which parents become responsible after hospitalization (Malin & Johnson, 2019). These unique needs often prevent parents from creating meaning from their experiences during and after NICU hospitalization (Chaney et al., 2016; Lasiuk et al., 2013). Parents frequently cope with feelings of uncertainty about the health of their child by managing information inputs through either an intensive pursuit of information or careful evasion of encounters that increase awareness of negative feelings. These two forms of information management strategies are similar to two of the symptom clusters of post-traumatic stress disorder: hyperarousal and avoidance (Santacroce, 2003). For parents in the NICU, uncertainty about the health of their infant may disrupt the critical processes of family and parental role attainment (Granrud et al., 2014; Obas et al., 2016; Malin & Johnson, 2019).

In the last decade, perinatal posttraumatic stress disorder (PPTSD) has been identified and described as a unique and often debilitating mental health disorder. PPTSD develops secondary to trauma either during pregnancy, birth or up to one year after delivery (McKenzie-McHarg et al., 2015). The risk for PPTSD is markedly increased for parents whose infants receive care in the NICU. Among these parents, up to 60% of women and 40% of men have reported symptoms of PPTSD; in contrast an estimated 9% of women whose infants do not require care in the NICU report symptoms of PPTSD (Aftyka et al., 2017; Vignato et al., 2017). A recent analysis noted the cost of hospitalization for women diagnosed with trauma-or stress-related mental health disorders is \$825 higher per delivery than for women without mental health disorders. Furthermore, women suffering from trauma-or stress-related mental health disorders have an 87% higher rate of morbidity compared to women without mental health disorders (Brown et al., 2021).

Early recognition of parents at risk for PPTSD is essential, as PPTSD is a risk factor for decreased healthy parent-infant attachment (Petit et al., 2016). Specifically, mothers with PPTSD have been found to experience significantly altered maternal-infant interactions at six and twelve months after birth (Petit et al., 2016). Parents suffering from post-traumatic stress are more likely to display controlling and less sensitive interactions with their infants and are at increased risk for intergenerational transmission of trauma from parent to child (Bosquet Enlow et al., 2014). Women with symptoms of PPTSD are also more likely to

report their infants as less easy to soothe and are more apt to report distress (Shaw et al., 2013) and their infants are at risk for lower developmental social skills at six months corrected gestational age (Forcada-Guex et al., 2011).

Previously identified risk factors for PPTSD in parents of infants in the NICU include mental health history, parent factors, and infant characteristics. History of mental health disorders, including both personal and family history of mental health have been associated with an increased risk for PPTSD (Greene et al., 2015; Holditch-Davis et al., 2015; Shaw et al., 2014). Other parent factors associated with PPTSD include parental perception of illness severity (Malin et al., 2019) and social support (Ford & Ayers, 2011). Infant characteristics such as severe medical complications are also risk factors for parental PPTSD (Hatters Friedman et al., 2013; Vinall et al., 2018; Malin et al., 2019).

This study was guided by The Uncertainty in Illness Theory (UIT) (Mishel, 1988). According to the UIT, uncertainty is not fundamentally a negative or positive state, instead it is how a person appraises and then copes with the uncertainty which affects their health and well-being. Three constructs undergird the framework of the UIT; the antecedents of uncertainty, appraisal of uncertainty, and coping with uncertainty (Mishel, 1988). At admission to the NICU, parents often experience feelings of uncertainty about the health of their infant. According to the UIT, the antecedents of uncertainty influence how parents perceive and understand the diagnosis and potential outcomes for their sick or premature infants. The pattern of infant clinical symptoms and condition is typically unfamiliar and unexpected for parents. Further, the parents own characteristics such as age, gender, and education set the stage for understanding and interpreting the NICU experience. Next, uncertainty is appraised, and it is through this process that one places value on uncertainty (Mishel, 1988). Finally, once appraisal of uncertainty is completed there is movement into the final construct of coping with uncertainty (Mishel, 1988). Parents of infants requiring NICU hospitalization report coping strategies such as positive reframing, religion, and self-blame, some of which are effective and some ineffective (Huenink & Porterfield, 2017).

The relationship between parental uncertainty in parents of infants requiring hospitalization in the NICU and PPTSD has not, to our knowledge, been evaluated. The purpose of this study was to explore parental uncertainty during and three months after NICU hospitalization and the relationship between uncertainty and PPTSD screened at three months after NICU discharge. Personal or family history of mental illness was used as a moderating condition as uncertainty may be interpreted and responded to differently by people with history of mental illness. There is no research to date about uncertainty and either personal or family history of PPTSD, but the potential differences in reactions to uncertainty raise the possibility of a moderating effect of personal or family history or mental illness on the relationship between uncertainty and PPTSD. Our team used a prospective design to examine the following aims and related hypothesis: Aim 1- determine how uncertainty changes overtime in parents of infants requiring NICU hospitalization and the parent and infant characteristics associated with parental uncertainty; hypothesis 1 - parents of infants requiring NICU hospitalization who experience high levels of uncertainty will display distinctly different infant and parent characteristics as compared to parents of infants who experience low levels of uncertainty; Aim 2 - examine the direct effect of

parental uncertainty during NICU hospitalization and the mediating effect of uncertainty at 3 months post-NICU hospitalization on the development of PPTSD; hypothesis 2 - parental uncertainty during NICU hospitalization will directly mediate uncertainty at three months post-NICU hospitalization and screening positive for PPTSD 3 months post-NICU hospitalization; Aim 3- assess the moderating effects of a personal or family history of mental illness on the relationship between parental uncertainty and PPTSD; hypothesis 3- personal or family history of mental illness will moderate parental uncertainty during NICU hospitalization and screening positive for PPTSD 3 months post-NICU hospitalization. The hypotheses are aligned with the tenets of the UIT in that parents in the NICU who experience high levels of uncertainty could have an altered appraisal of their experience and therefore be less tolerant and less able to cope with uncertainty. This reduction in tolerance and/or ability to cope with the experience of uncertainty may, for some parents, result in a continued assessment of a threat to their infant's illness. This threat may then be manifested through symptoms of PPTSD following the NICU hospitalization experience.

MATERIALS & METHODS

Sample and Setting

Our team collected data from parent-infant dyads hospitalized in a Midwestern 70-bed, level four NICU as part of a larger study that evaluated the effectiveness of a home naso-gastric feeding program following NICU discharge (Lagatta et al., 2021). The study NICU has an admission rate of about 800 infants annually. Psychologists are permanent members of the NICU staff and the NICU has a well-established family support program. Palliative care services are routinely consulted for infants who will require long-term complex care. We enrolled eligible parent-infant dyads from September 2018 – March 2020. Inclusion criteria were: one parent of any age whose infant (or multiple infants) was never previously discharged from the hospital regardless of age of the parent; parent was fluent in English; infant who was at least 14 days old at the time of enrollment and hospitalized in the NICU at the time of data collection. Exclusion criteria for enrollment included: parents who would not be caring for the infant after discharge, parents of infants whose death appeared imminent as determined by the attending physician, and parents of infants who would be transferred to the cardiac intensive care unit prior to discharge. Parents of infants who died after initial enrollment were excluded from the three-month post-discharge data collection. Only one parent per infant was allowed to participate in the study. Rule-of-thumb for sample size needed for a structural equation model was used, indicating that a size of at least 200 dyads would provide power at 0.80, with $\alpha = 0.05$ to detect a small, but non-trivial, effects of 0.20 SD (Boomsma, 1982).

Measures—*Parental Perception of Uncertainty Scale (PPUS)* was used to measure mothers' and fathers' appraisal of uncertainty about their infant's illness. The PPUS is a 31-item instrument that includes questions related to ambiguity, lack of clarity, lack of information, and unpredictability (Mishel, 1983). The scaling format is a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree), yielding a total score between 31 and 155. Higher scores indicate greater perception of uncertainty. The four subscales of the PPUS include ambiguity, lack of clarity, lack of information, and unpredictability (Mishel, 1983).

Reliability of the scale has been reported in samples of mothers and fathers with Cronbach alphas between 0.86 and 0.87 (Madeo et al., 2012; Santacroce, 2001). Content and construct validity of the PPUS has been evaluated, with one and four factor models emerging in other populations of parents of children not in the NICU (He, You, Cheng, & Bi, 2016; Madeo et al., 2012; Mozeon et al., 2014; Santacroce, 2001). The total scale was used for this analysis and the Cronbach's alpha reliability estimates for this sample was 0.92 at the time of enrollment and 0.91 three months after NICU hospitalization. Average PPUS scores reported in parents of children not typically cared for in the NICU have ranged between 70.3 and 83.0 (Lipinski et al., 2006; Mishel, 1983). Parents in our study completed the PPUS at the time of enrollment and again at three months after discharge from the NICU.

Perinatal Post-traumatic Stress Disorder Questionnaire (PPQ) was used to measure PPTSD. The PPQ is a validated, 14-item questionnaire assessing PPTSD symptoms associated with the birth of an infant (Callahan et al., 2006). Scoring is completed using a five-point Likert scale (0 = not at all, 4 = more than a month). Scores ≥ 19 warrant clinical treatment (Callahan et al., 2006). Reliability and construct validity have been reported in samples of mothers and fathers, with Cronbach alphas between 0.85 – 0.90 (Callahan et al., 2006; DeMier R.L, Hynan M.T., Harris H.B., Manniello R.L., 1996). In this study, parents completed the PPQ three months after the infant's discharge from the NICU; this timeframe was selected because stress symptoms cannot be classified as post-traumatic until at least one month after the stressful event (American Psychiatric Association, 2013). To use the PPQ as an outcome variable in our analysis, the PPQ scores were totaled and the total score was categorized in two groups, where 0 = parents who did not screen positive for PPTSD (score <19) and 1 = parents who screened positive for PPTSD (score ≥ 19). The dichotomized PPQ score is commonly used in research and clinical practice to offer clarity of interpretation in differentiating respondents who should be further screened for confirmation of PPTSD. The Cronbach's alpha reliability estimate for this sample was 0.84.

Parental Characteristics: Data on antecedents of uncertainty and risk factors for PPTSD were collected during NICU hospitalization. These characteristics included: parental age (Chan et al., 2020; Cole et al., 2015); race (Cole et al., 2015); social determinants of health including, highest level of education, housing, access to transportation, and employment (Bolívar Montes & Montalvo Prieto, 2016; Cole et al., 2015; Gondwe et al., 2017); and history of personal and family mental illness (Chan et al., 2020; Cole et al., 2015; Toly et al., 2019). All data were collected from parents by self-report at enrollment.

Infant Characteristics: Data about infant illness severity hypothesized to be antecedents to parental uncertainty and risks for PPTSD (Malin et al., 2019) were collected from the electronic health record (EHR). These infant characteristics that were indicators of the clinical condition included days of mechanical ventilation, bronchopulmonary dysplasia (BPD), need for vasopressors, hypoxic ischemic encephalopathy (HIE) requiring cooling, palliative care consultation, seizures, and gestational age at birth.

Procedures—Institutional review board approval was obtained from Children's Wisconsin prior to beginning the study. Eligibility for participation was determined through screening of the electronic health record by the research team. Participants were approached during

their infant's NICU hospitalization by a member of the research team. The purpose of the study was explained to the parents and their written informed consent was obtained. Parent characteristics data were collected at time of enrollment; infant data were collected from the EHR at the time of hospital discharge. Parents completed the PPUS and PPQ instruments directly on a study tablet. All data were input and recorded electronically using REDCap (Harris et al., 2009). Parents were asked at the initial point of contact for their preference for follow-up communication (email or phone); the researchers contacted the parents for the three-month data collection by their preferred method. Information regarding parental stress, perinatal post-traumatic stress, and local mental health resources were given to all parents in the study at the time of enrollment. Additionally, all parents received a stipend of \$20.00 for their time after each point of data collection.

Statistical Analysis—Data analyses were performed using STATA (StataCorp. 2017). We first examined data using descriptive statistics. Missing data were evaluated for all variables and assessed for missing completely at random using Little's test (Little, 1988). Since Little's test supported the assumption of missing completely at random, multiple imputation by a system of chained ordered logit equations was used to impute the missing data. Descriptive statistics were calculated for all study variables.

For aim 1, to assess how parental uncertainty during NICU hospitalization changed over time and to identify what parental and infant characteristics are associated with uncertainty, we compared parental uncertainty during NICU hospitalization and again three months after discharge for each of the parent and infant characteristics using simple mean contrasts, and Becker's adjusted standardized mean difference (effect size) for paired data (Becker, 1988). Due to the large number of contrasts, positive False Discovery Rate (pFDR—the expected number of false positives out of all tests) was used to measure multiple hypothesis testing error instead of p value (Benjamini & Hochberg, 1995).

For aim 2 and 3 we computed a combined moderated-mediating structural probit model (Muthen, 1979) using MPlus for the dichotomous outcome of PPTSD. More complex statistical models, such as structural models, generally require large sample sizes. To deal with the model complexity and smaller sample sizes in our study we used an empirical Bayesian estimation approach in our probit model (Lee & Song, 2004; Ozechowski, 2014). We first examined associations between parent and infant characteristics and screening results for PPTSD by contrasting the proportions of parents who screened positive for PPTSD vs parents who screened negative for PPTSD for each specific characteristic. We then selected the infant and parent characteristics that were significant ($p < 0.05$ or clinically meaningful measures of clinical severity) with sufficient sample size in the bivariate analyses to be included as exogenous variables for the probit model. The probit model explored the directional relationships of PPUS during hospitalization and at three months post discharge with PPTSD (PPQ scores categorization as positive vs. negative screen for PPTSD) and the indirect (mediating) relationship of PPUS at three months on the relationship of PPUS during hospitalization with PPTSD (aim 2). Parent self-report of personal or family history of mental illness, a previously reported risk factor for PPTSD (Chan et al., 2020; Cole et al., 2015; Toly et al., 2019), was included in the model as a moderating condition (aim 3), so that relationships could be examined for those with

and without mental illness history. Responses were treated as missing data if the parent responded to the question about personal or family history as “don’t know” (n=8).

RESULTS

Demographics

Of the 372 parents approached from September 2018 through May 2020, 333 consented to participate; 319 were discharged from the hospital and still eligible for three-month follow-up by the end of the study period. Of those eligible for follow-up, 253 (79%) completed data collection at three-months post-NICU discharge. Eight participants were dropped from the cohort because of large amounts of incomplete data, leaving 245 parent-infant dyads in the final sample. Based on an original sample size of 319, 23.8% (n=75) of the binary outcome of screening positive or negative for PPTSD was missing. Within the model, 2.45% (n=5) of demographic variables were missing, bringing the analytic model sample size to 239 due to listwise deletion. The median day of life at enrollment was 21 days (IQR 17-31). Parent and infant sample characteristics are displayed in Table 1.

Aim 1: Parental Perception of Uncertainty Overtime and Parent/Infant Characteristics

PPUS scores at time two (three months after NICU discharge) decreased from time one (the time of enrollment while in the NICU) ($M = 63.8$ [$SD=16.8$, range 61-87] vs $M=67.7$ [$SD=16.8$, range 62-79], $p < 0.001$). PPUS scores over time for infant and parent characteristics are displayed in Table 2. The effect size in changes of PPUS scores was in the expected direction. Parent age and parent education displayed a progressive decrease in effect size with increases in value of the subcategories. Conversely, length of NICU hospitalization and severity of BPD displayed a progressive increase in effect size with increases in value of the subcategories. Some characteristics and subgroups within characteristics did not display a statistically significant effect. These characteristics included parents of term infants, parents of infants receiving palliative care consultation, parents of infants requiring over 30 days of ventilation, parents of infants with seizures, parents 31 years old, highest level of parent education, as well as parents who were unemployed/ otherwise unemployed (i.e.: student or not seeking work).

Aim 2 and 3: Direct and Mediating Effects of Uncertainty on PPTSD and Moderating Effects of Personal and Family History of Mental Illness

Thirty-six percent of the parents ($n = 91$) enrolled in the study screened positive for PPTSD three months after discharge from the NICU. Parents who screened positive for PPTSD three months after NICU discharge had higher levels of uncertainty at both points in time. At enrollment the mean PPUS score in parents who screened positive for PPTSD was 71.6 ($SD = 17.2$) as compared to parents who screened negative with a mean PPUS score of 65.4 ($SD = 16.2$) ($p < 0.001$). Similarly, three months after discharge, the mean PPUS score in parents who screened positive for PPTSD was 67.6 ($SD = 16.8$) as compared to parents who screened negative for PPTSD with a mean PPUS score of 60.4 ($SD = 16.2$) ($p < 0.001$).

Variables included in the structural probit model were selected based on bivariate relationships between infant and parent characteristics and screening positive for PPTSD

(Table 3). Parents who screened positive for PPTSD had higher rates of self-reported history of mental illness and self-reported history of family mental illness. Parents screening positive for PPTSD also had more infants requiring over 30 days of mechanical ventilation, vasopressor support, and severe BPD than parents who screened negative for PPTSD. These variables were included in the probit analysis along with infant gestational age which was a clinically relevant infant characteristic indicative of clinical severity. Although NICU length of stay was also significantly associated with screening positive for PPTSD, this variable correlated highly with the infant variables and thus was not included.

Table 4 displays the results of a combined moderation/mediation structural probit analysis of predictors of PPTSD. No direct or indirect/mediation effect of PPUS during hospitalization or at three months post-discharge on screening positive for PPTSD was evident in parents with a personal or family history of mental illness. In parents who did not report self or family history of mental illness, there was also no direct effect of PPUS during hospitalization but a direct effect of PPUS at three months post-discharge on screening positive for PPTSD was evident, with higher levels of uncertainty associated with greater likelihood of screening positive for PPTSD ($\beta = 0.678, p < 0.001$). There was however an indirect, mediating effect of PPTSD from PPUS during hospitalization through PPUS at three months ($\beta = 0.276, p < 0.001$). Supplemental Figures 1 and 2 displays path diagrams of the moderated mediating relationships among the variables.

Both moderated-mediated models of mental illness history fit the data well (both with posterior predictive p -values > 0.80). Some exogenous variables (parent/infant characteristics) were significant in both models (gestational age and BPD).

DISCUSSION

Our results point to a previously unreported relationship between parental uncertainty following an infant's NICU hospitalization and screening positive for PPTSD after discharge from the hospital. This is, to our knowledge, the first study to use the PPUS to measure parental uncertainty and its relationship to screening positive for PPTSD. Uncertainty was higher during hospitalization than after NICU discharge. While a direct association of uncertainty during NICU hospitalization with screening positive for PPTSD was not evident, the indirect pathway from uncertainty during hospitalization to uncertainty at three months to screening positive for PPTSD in parents with no prior personal or family history of mental illness suggest the importance of proactively evaluating and addressing parental uncertainty both during and after NICU hospitalization.

Viewed within the lens of The Uncertainty in Illness Theory, our findings confirm the utility of this theory for understanding the NICU parent experience of uncertainty. The parent's appraisal of the uncertainty is conditional on certain antecedent parental and infant factors. For some parents of infants requiring NICU hospitalization, the appraisal of their feelings of uncertainty presents a threat that, if not addressed through the parents' own responses or interventions of the health care team, may lead to an increased risk for adverse mental health outcomes in the post-discharge period; specifically screening positive for PPTSD. Since

uncertainty can be assessed as either a threat or an opportunity (Mishel, 1988), healthcare providers have the opportunity to help parents reframe uncertainty while in the NICU.

Our findings are consistent with these previous reports that describe elevated levels of parental uncertainty in parents with sick children (Fedele et al., 2011; Kerr & Haas, 2014). We expected that parental uncertainty about their infant's health would decrease after NICU discharge. There is no clinically based anchor of uncertainty to determine whether between-parent PPUS differences are clinically meaningful versus statistically significant. Our findings, in general, support the expectation that uncertainty decreases after discharge from the NICU. This was not true, though, for parents of term infants, parents of infants requiring <60 days of NICU hospitalization, parents of infants receiving palliative care consultation, parents of infants requiring over 30 days of ventilation, parents of infants with seizures, parents 31 years old, highest level of parent education, as well as parents who were unemployed/otherwise unemployed (i.e.: student or not seeking work). That parental uncertainty occurs with relative frequency and at various levels most likely speaks to the nature of the diagnosis leading to the need for NICU care, fear for the short and long-term prognosis and future normalcy, and the compounding stress associated with social determinants of health, such as lack of employment and transportation which may create additive uncertainty.

The use of clear communication, family-centered care, and understanding of how parents live with uncertainty are all necessary to support parents prior to discharge from the NICU (Krick, J.A. et al., 2020). As healthcare providers facilitate coping with uncertainty in this population, they may contribute to reducing the risk for development of PPTSD; however, their efforts are hampered by the lack of availability of published intervention studies focused on managing uncertainty in the NICU to provide a basis for evidence-based practice. Often families are discharged from the NICU with follow-up care with a pediatric developmental specialist but with very little in the way of structured mental health follow-up. Our findings support the need for parental mental health support after the infant's discharge from the NICU. Policies, such as expanding Medicaid coverage for postpartum women beyond 60 days, may offer frameworks to help implement these types of mental health support.

The relationships between health, stress, allostatic load, and social determinants of health have previously been described (Braveman & Gottlieb, 2014). Our finding that lack of employment and lack of transportation are associated with uncertainty and illness in parents of infants in the NICU point to opportunities for health care providers to proactively assess for needs. Asking about social determinants of health at time of NICU admission and continual evaluation of family needs and feelings about uncertainty allows for targeted interventions such as anticipatory guidance and consultation with support services.

Our findings support the notion that PPTSD is a multifactorial process with many different parental and infant risk factors (Beck & Harrison, 2017). These findings are consistent with previous research identifying parental mental health and parental perception of illness as risk factors for PPTSD (Aftyka et al., 2014; Granrud et al., 2014; Malin et al., 2019). In our sample, among parents without mental illness histories, uncertainty during the NICU

hospitalization was indirectly associated with PPTSD through uncertainty at three months after NICU discharge. However, no such association was observed in parents with history of personal or family mental illness. This finding underscores the importance of holistic mental health support and screening for parents without a personal or family history of mental illness. These parents are less likely to have access to or be referred mental health services as compared to parents with a personal or family history of mental illness. Understanding relationships between NICU screening of mental health and post NICU discharge mental health outcomes will be important in future research and clinical work. Asking about parental mental health histories and screening parents for concurrent mental health disorders, like depression and anxiety, while their infant is in the NICU should become a standard of NICU care. However, services to support continuing assessment of both uncertainty and PPTSD in the post-discharge period need to be developed to assure adequate identification of parents who have continuing uncertainty and/or who develop PPTSD in the months following NICU discharge. The findings from our study underscore the importance of these discussions and screenings, as these are risk factors that impact mental health long after the infant's discharge from the NICU. This follow-up is particularly important for parents who have no prior mental illness history. The lack of association of uncertainty to PPTSD in parents with a history of mental illness in our study may be related to early identification, access, and continuation of ongoing mental health care for parents with a history of mental illness.

Infant characteristics were not as strongly associated with screening positive for PPTSD as previously reported in other samples of parents in the NICU (Feeley et al., 2011). This might be because our study included any infant requiring NICU hospitalization and not just infants with very low birth weight. There were a few infant characteristics in the NICU that should be utilized by healthcare providers as indicators of risk for screening positive for PPTSD in parents after their infants' discharge. These markers of infant illness severity include need for vasoactive pressor agents, palliative care consultation, lower gestational age at birth, HIE requiring cooling, and mechanical ventilation for over a month. Our combined results of the parent/infant characteristic associations with both uncertainty and PPTSD support the notion that having a very sick or premature infant in the NICU can be traumatic for parents and may be antecedents to prolonged symptoms of traumatic stress.

This study has several limitations. First, it was a single-center study limited to English speaking parents; rates of uncertainty and screening positive for PPTSD as well as the distribution of parent and infant characteristics may be different in samples from other cultures and geographic locations. It is also possible that the uncertainty reported was associated with risk factors other than requiring NICU hospitalization. Second, we were not able to analyze for differences between mothers and fathers as the sample of fathers was very small. Third, our sensitivity analysis for the final group of 245 parents as compared to the original 319 parents found significant differences in insurance, racial makeup, and education. Fourth, assessment of personal and family history of mental illness was obtained via self-report and not a clinical interview. Fifth, the analytic model included a range of possible parent and infant confounders, but there are other parent descriptors and infant clinical variables that may affect parental uncertainty and the relationship to PPTSD. For example, measurements of resiliency and possible protective factors against uncertainty

and PTSD were not measured. Finally, while we obtained data three months after NICU discharge, it is unknown how many of the parents who screened positive for PTSD experienced resolution of symptoms and distress with further passing of time, which could only be captured with longer follow-up.

Conclusion

The possibility that parents have continuing feelings of uncertainty that contribute to the development of PTSD after the infant's discharge from the hospital provides opportunities for healthcare providers to intervene to improve parental mental health. The results point to the potential importance of proactively evaluating and addressing parental uncertainty during and after NICU hospitalization. Resources such as embedding mental health services into the NICU care team and follow-up clinics in addition to leveraging telemedicine services to bridge gaps in access need to become the standard of care (Hynan et al., 2015). There is a critical need for moving research in this area from knowledge of associations to intervention development. Future research should focus on nursing interventions to support parents as they learn to cope with uncertainty in the NICU as prevention for PTSD after NICU discharge. Clinical education for health care providers is needed regarding the importance of and methods for screening for parental mental health in the NICU and the need to continue mental health screening and care beyond the time of discharge.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Sample Characteristics

Variable	Total (N)	%	Mean	Standard Deviation	Minimum – Maximum
Infant Characteristics					
Gestational Age at Birth					
22-25 weeks	34	10.7%			
26-28 weeks	37	11.6%			
29-31 weeks	60	18.8%			
32-36 weeks	119	37.3%			
>37 weeks	69	21.6%			
Palliative Care Consultation					
Yes	8	3%			
No	235	97%			
Length of NICU Hospitalization in Days	324		68.1	65.6	13-387
Days of Ventilation					
0	140	43.9%			
1-7	90	28.2%			
8-30	38	11.9%			
>30	51	16%			
Required Vasopressor Support					
Yes	73	23%			
No	243	77%			
Broncho Pulmonary Dysplasia Severity					
Missing	5	1.6%			
None	218	68.3%			
Mild	7	2.2%			
Moderate	35	11%			
Severe	54	16.9%			
Seizures Requiring Medication					
Yes	8	2.5%			
No	311	97.5%			
Hypoxic Ischemic Encephalopathy Requiring Cooling					
Yes	5	98.4%			
No	314	1.6%			
Parent Characteristics at time of Enrollment					
Parent Age			29.9	5.59	17-43
Relationship to Infant					
Mother	310	97.2%			
Father	9	2.8%			
Race					

Variable	Total (N)	%	Mean	Standard Deviation	Minimum – Maximum
Black or African American	76	24%			
White	214	67.3%			
Asian	8	2.5%			
American Indian or Alaska Native	3	0.1%			
Other	17	5.3%			
Housing					
Has housing	236	97%			
Does not have housing	4	2%			
Prefer not to answer	3	1%			
Highest Level of Education Completed					
Have not finished high school	22	6.9%			
High school graduate	62	19.4%			
Some college or technical school	81	25.4%			
College or technical school graduate	115	36%			
Graduate school	39	12.2%			
Insurance Type					
Public	174	54%			
Private	145	45%			
Lack of Transportation					
Yes	11	5%			
No	231	95%			
Employment					
Unemployed	52	21%			
Part-time or temporary work	35	14%			
Full-time	134	55%			
Otherwise unemployed	19	9%			
Prefer not to answer	3	1%			
History of mental illness					
Yes	103	43%			
No	131	54%			
Don't know	8	3%			
Family history of mental illness					
Yes	98	40%			
No	132	54%			
Don't know	13	6%			
Parental Perception of Uncertainty Scale					
Enrollment	319		68.9	16.9	31-80
3 months after discharge	245		63	16.8	31-78
Perinatal Posttraumatic Stress Disorder					

Variable	Total (N)	%	Mean	Standard Deviation	Minimum – Maximum
Screened positive	91	36%			
Screened negative	162	64%			

Note. possible scores on the Parental Perception of Uncertainty Scare range from 31 to 155. Total possible scores on the Perinatal Posttraumatic Stress Disorder Questionnaire range from zero to 56.

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Table 2

Parental Perception of Uncertainty Over Time

Variables	NICU enrollment		3 months after NICU		SD	Effect size NICU enrollment to 3 months after NICU discharge	95% CI: NICU enrollment to 3 months after NICU discharge	Positive false discovery rate
	n	M	n	M				
Gestational Age								
22-25 WEEKS	34	76.2	14.6	27	67.2	15	-0.96 to -0.21	<0.001
26-28 WEEKS	37	73.8	17.2	29	63.2	13.6	-1.04 to -0.18	<0.001
29-31 WEEKS	60	62.6	17.4	43	56.6	15.2	-0.67 to -0.01	0.04
32-36 WEEKS	119	66.6	16.4	95	61.6	17.6	-0.37 to 0.37	0.18
37 WEEKS	69	72.2	16	51	68.8	17.4	-0.41 to 0.41	0.57
Length of NICU Hospitalization in Days								
28 days	82	63.9	14.5	60	61.1	16.4	-0.29 to 0.24	0.86
29-60 days	122	66.3	17.9	97	62.2	17.8	-0.38 to 0.02	0.12
61-90 days	43	74.4	15.2	31	64	16.2	-0.98 to -0.20	0.01
91 days	72	75.6	16.9	57	65.9	15.7	-0.87 to -0.28	<0.01
Palliative Care Consultation								
No	314	69	16.8	240	63	16.8	-0.40 to -0.14	<0.001
Yes	5	66.6	22	5	69.4	16.8	-1.26 to 0.34	0.26
Ventilator Days								
0 DAYS	140	64.5	16.3	104	61.2	17	-0.39 to -0.02	0.05
1-7 DAYS	90	67.7	16.9	72	62.6	17	-0.58 to -0.03	0.05

Variables	NICU enrollment			3 months after NICU			SD	Effect size NICU enrollment to 3 months after NICU discharge	95% CI: NICU enrollment to 3 months after NICU discharge	Positive false discovery rate
	n	M	n	M	n	M				
8-30 DAYS	38	75.6	18.8	28	63.8	16.8	16.8	-0.48	-0.81 to -0.14	0.01
>30 Days	51	72.4	15	41	68.2	15.6	15.6	-0.27	-0.62 to 0.08	0.18
Required Pressor Support										
No	246	66.4	16.7	186	62.2	16.8	16.8	-0.25	-0.40 to -0.11	<0.001
Yes	73	72.0	16.8	59	65.8	16.8	16.8	-0.37	-0.65 to -0.08	0.03
BPD										
None	218	65.5	16.6	164	62.2	17.4	17.4	-0.20	-0.36 to -0.04	0.03
Mild	7	66.3	20.8	6	61.6	13.6	13.6	-0.19	-0.98 to 0.60	0.59
Moderate	35	70.6	14.6	28	62	16	16	-0.57	-1.0 to 0.14	0.03
Severe	54	76.6	15.2	43	68.6	15.2	15.2	-0.52	-0.83 to -0.17	<0.001
Seizures										
No	308	67.2	16.8	237	62.6	16.8	16.8	-0.27	-0.40 to -0.14	<0.001
Yes	11	85.7	15.8	8	76.3	13.6	13.6	-0.81	-1.93 to 0.32	0.25
Hypoxic Ischemic Encephalopathy Requiring Cooling										
Yes	5	66.6	22	5	69.4	16.8	16.8	0.10	-0.71 to 0.91	<0.01
No	314	68.9	16.9	240	62.9	16.8	16.8	-0.29	-0.42 to -0.16	0.76
Parent Age										
18	4	81	24.2	1	78					N/A
19-25	68	72.3	16.4	54	62.8	17.5	17.5	-0.51	-0.73 to -0.26	<0.01

Variables	NICU enrollment			3 months after NICU			SD	Effect size NICU enrollment to 3 months after NICU discharge	95% CI: NICU enrollment to 3 months after NICU discharge	Positive false discovery rate
	n	M	SD	n	M	SD				
26-30	88	65.8	15.7	69	60.2	14.7	-0.33	-0.56 to -0.09	0.01	
31-35	107	70	17.1	83	65.4	17.3	-0.17	-0.39 to 0.05	0.13	
36	47	66.7	18.3	34	63.8	18.3	-0.07	-0.50 to 0.36	0.76	
Race of Mother										
Black/African American	76	70.2	15.2	48	65.6	14.4	-0.29	-0.60 to 0.02	0.09	
White	214	67.3	17.4	177	62.4	17.6	-0.28	-0.44 to -0.13	<0.001	
Asian	8	61.7	10.6	6	66.6	12	0.55	-0.58 to 1.69	0.49	
American Indian/Alaska Native	3	77.5	2.6	2	67.6	14.8	0	0 to 0.5	0.57	
Other	17	67.1	21.4	11	61.4	18.6	-0.25	-0.72 to 0.22	0.32	
Highest Level of Education Completed										
Have not finished high school	22	77.9	16.6	14	72.3	17.8	-0.41	-0.92 to 0.09	0.16	
High school graduate	62	68.3	16.6	44	64.1	16.8	-0.24	-0.52 to 0.04	0.13	
Some college or technical school	81	69.3	16.7	57	61.1	16.2	-0.29	-0.56 to -0.03	0.05	
College or technical school graduate	115	67.3	17.4	98	61.8	17.2	-0.29	-0.51 to -0.07	0.02	
Graduate school	39	68.7	16.1	32	64.7	15.9	-0.16	-0.54 to 0.21	0.47	
What is your Housing Situation Today?										
"I have housing"	308	67.3	16.8	238	62.6	16.8	-0.28	-0.41 to -0.14	<0.001	
"I don't have housing"	5	76.2	7.9	4	66.8	12.8	-0.87	-1.6 to -0.11	0.08	
Insurance Type										

Variables	NICU enrollment		3 months after NICU		SD	Effect size NICU enrollment to 3 months after NICU discharge	95% CI: NICU enrollment to 3 months after NICU discharge	Positive false discovery rate	
	<i>n</i>	<i>M</i>	<i>n</i>	<i>M</i>					
Public	174	70.1	17	125	65.2	16.8	-0.28	-0.46 to -0.11	<0.01
Private	145	65.3	16.4	120	60.8	16.6	-0.28	-0.47 to -0.08	0.02
Has a lack of transportation kept you from Important appointments?									
No	295	67.4	16.8	232	62.8	16.6	-0.27	-0.41 to -0.14	<0.001
Yes	23	75.6	15.4	12	69.6	18.6	-0.37	-0.87 to 0.13	0.25
Employment									
Part time or temporary work	44	71.4	16.8	36	62.2	17.8	-0.54	-0.86 to -0.21	<0.01
Full time employment	173	66.4	16.8	134	62.4	16.6	-0.23	-0.41 to -0.05	0.02
Otherwise unemployed	22	67.2	16	19	62.6	16.6	-0.27	-0.68 to 0.14	0.25
Prefer not to answer	6	78.3	2.5	3	87 (19.2)		1.9	-0.94 to 4.9	0.59

Note. table two displays the associations with parent uncertainty over time. Statistical significance was assessed by a false positive discovery rate of <0.05 to account for multiple comparisons of the two different time points.

Table 3

Infant and Parent Characteristics Associated with Screening Positive or Negative for Perinatal Post-Traumatic Stress Disorder (PPTSD)

Characteristics	Total (N)	Screened Positive for PPTSD	Screen negative for PPTSD	Chi2/T-test	
Infant Characteristics					
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Length of NICU Hospitalization in Days	243	81.5	69.9	56.4	57.4 0.01
		<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
Gestational Age					0.16
22-25 weeks	27	13	48	14	52
26-28 weeks	28	14	50	14	50
29-31 weeks	43	12	28	31	72
32-36 weeks	95	29	32	66	68
37 weeks	50	18	36	32	64
Palliative Care Consultation					0.10
Yes	8	5	63	3	37
No	235	81	34	154	66
Ventilator Days					<0.001
0 days	103	26	25	77	75
1-7 days	71	28	39	43	61
8-30 days	28	9	32	19	68
>30 days	41	23	56	18	44
Vasopressors					<0.001
Yes	59	30	51	29	49
No	184	56	30	128	70
BPD					0.10
None	163	54	33	109	67
Mild	6	1	17	5	83
Moderate	27	8	30	19	70
Severe	43	22	51	21	49
Seizures					0.91
Yes	6	2	33	4	67
No	237	84	35	153	65
Hypoxic Ischemic Encephalopathy					0.24
Yes	5	3	60	2	40
No	238	83	35	155	65
Parent Characteristics					
		<i>M</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>
Age	231	29.9	5.88	29.7	5.05 0.84
		<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>

Characteristics	Total (N)	Screened Positive for PPTSD	Screen negative for PPTSD	Chi2/T-test
Race				0.13
Black or African American	46	13	28	33
White	177	70	40	107
Asian	6	0	0	6
American Indian or Alaska Native	2	0	0	2
Other	11	3	27	8
Housing				0.48
Has housing	236	83	35	153
Does not have housing	4	1	25	3
Prefer not to answer	3	2	67	1
Education				0.61
Have not finished high school	13	7	54	6
High school graduate	44	13	30	31
Some college or technical school	57	21	37	36
College or technical school graduate	98	34	35	64
Graduate school	31	11	35	20
Lack of transportation				0.05
Yes	11	7	64	4
No	231	79	34	152
Employment				0.73
Unemployed	52	18	35	34
Part-time or temporary work	35	12	34	23
Full-time	134	50	37	84
Otherwise unemployed	19	6	32	13
Prefer not to answer	3	0	0	3
History of mental illness				<0.001
Yes	103	52	50	51
No	131	30	23	101
Don't know	8	3	37	5
Family history of mental illness				<0.001
Yes	98	47	48	51
No	132	34	26	98
Don't know	13	5	38	9

Note. table 3 displays the relationships between infant and parent characteristics and screening positive for PPTSD 3 months after NICU discharge.

Table 4
Moderated-mediating probit model of parental uncertainty and screening positive for PPTSD after NICU discharge

	Positive for Personal or Family History of Mental Illness N=174				No Personal or Family History of Mental Illness N=135				Contrast	
	Est	SD	p-value	95% CI	Est	SD	p-value	95% CI	Difference (95% CI)	p-value
Direct Effects: Positive Screen for PPTSD										
Uncertainty at NICU enrollment	0.298	0.199	0.12	-0.043 to 0.0676	0.094	0.238	0.66	-0.431 to 0.516	-0.204	0.25
Uncertainty 3 months after NICU discharge	0.189	0.2	0.32	-0.219 to 0.592	0.678	0.229	<0.001	0.27 to 1.192	0.049	0.05
Indirect Effects: Positive Screen for PPTSD										
Uncertainty at enrollment → Uncertainty 3 months after NICU discharge → Screen + for PPTSD	0.093	0.099	0.32	-0.109 to 0.275	0.276	0.118	<0.001	0.077 to 0.510	0.154	0.12
Exogenous Moderating Variables										
Uncertainty at NICU enrollment on										
Gestational age	0.029	0.013	0.01	0.004 to 0.055	0.025	0.013	0.04	0.001 to 0.051	-0.004	0.41
Ventilator days	0.011	0.051	0.8	-0.071 to 0.117	0.086	0.054	0.08	-0.039 to 0.196	0.074	0.16
Vasopressor support	0.25	0.114	0.05	[-0.003 to 0.432]	-0.069	0.12	0.44	-0.345 to 0.145	-0.319	0.03
BPD	0.346	0.144	<0.01	0.079 to 0.675	0.248	0.135	0.02	0.051 to 0.480	-0.098	0.31
Uncertainty 3 months after NICU discharge on										
Uncertainty at NICU enrollment	0.478	0.076	<0.01	0.314 to 0.614	0.414	0.093	<0.01	0.23 to 0.587	-0.064	0.30
Gestational age	0.04	0.014	<0.01	0.013 to 0.067	0.018	0.017	0.18	-0.010 to 0.058	-0.022	0.16
Ventilator days	0.041	0.052	0.32	-0.050 to 1.67	0.078	0.060	0.026	-0.029 to 0.194	0.037	0.32
Pressor support	0.018	0.118	0.87	-0.220 to 0.227	-0.079	0.118	0.54	-0.314 to 0.184	-0.097	0.28
BPD	0.187	0.136	0.19	-0.13 to 0.435	0.088	0.153	0.54	-0.241 to 0.439	-0.099	0.31

Abbreviations: Est = parameter estimate, SD = standard deviation, BPD = bronchopulmonary dysplasia

Note. table 4 displays the estimates for the empirical Bayesian Moderated-Mediated Probit Model using a stacked model approach with personal or family history of mental health illness as a moderating condition.