Minimizing Parental Posttraumatic Stress Disorder in the NICU:

An Efficacy Analysis of Trauma Counseling

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Abstract

The birth of a new baby is known to be a joyful time for families. However, such a treasured experience can quickly reroute in a matter of moments which leaves the family feeling helpless, frightened, and guilty. The innate process of bonding and attachment is interrupted by the resuscitative course following a traumatic birth. Separation, grief, anger, and fear promote what's being deemed more and more frequently as parental posttraumatic stress disorder (PTSD). Rates of parental PTSD associated with separation at birth are equivalating those of post-partum depression and post-partum psychosis. Emotionally unstable parents are unable to adequately care for their newborn for both short and long term needs. Facilitation and support of the parental role in an altered environment, such as a neonatal intensive care unit (NICU), is thought to create opportunities for relationship security. Establishment of an emotionally invested caregiver has been proven to minimize sequelae of the NICU patient, reduce length of stay, cut readmission rates, and lower the incidence of failure to thrive post-discharge. A parental psychosocial program was instituted in a 32-bed NICU within a southwest children's hospital. The program efficacy was analyzed several months after implementation. Results are concurrent with the thought that individual counseling for NICU families reduces stress scores and improves patient satisfaction at discharge.

Keywords: NICU, parental PTSD, post-partum depression, parental empowerment, neonatal attachment, neonatal bonding, kangaroo care, non-nutritive breastfeeding, parental rounding, neonatal parental role, neonatal intensive care, posttraumatic stress disorder

Parental Posttraumatic Stress Disorder

The birth of a new baby is known to be a joyful time for families. However, such a treasured experience can quickly reroute in a matter of moments which leaves a family feeling helpless, frightened, and guilty. While a variety of distressing reactions are normative during this time, significant and prolonged parental distress, including posttraumatic stress disorder, are of great clinical concern (Aftyka, Rybojad, Rozalska-Walaszek, Rzoñca, & Humeniuk, 2014).

Problem Statement

It has been emphasized that posttraumatic stress disorder (PTSD) observed in parents negatively affects the well-being of their baby (Shaw et al., 2014b). Mothers with greater symptoms of PTSD are less sensitive and effective at structuring interaction with their infant (Aftyka, Rybojad, Rozalska-Walaszek, Rzoñca, & Humeniuk, 2014). Bellini (2009) shares that 26 to 41% of mothers who experience the neonatal intensive care unit (NICU) report PTSD symptoms compared with the one to six percent as reported from mothers who have healthy deliveries. The symptoms are often found to persist six months or longer (Bellini, 2009). Symptoms of PTSD that are present after six months are associated with an increased risk for an insecure and disorganized mother-infant attachment relationship at 13 months of age (Aftyka, Rybojad, Rozalska-Walaszek, Rzoñca, & Humeniuk, 2014). Lasiuk, Comeau, and Newburn (2013) state the symptoms can last up to 18 months during which time the role of the parent is inhibited. Without adequate performance of the parental role, the health and overall progress of the at-risk infant will inevitability fail which contributes to prolonged illness of the infant, failure-to-thrive, and elevated readmission rates (Lasiuk, Comeau, & Newburn, 2013).

Furthermore, the illness and death of a loved one results in an annual loss of nearly $40 billion in wages and health recovery costs in the United States (Youngblut, Brooten, Cantwell, del Moral, & Totapally, 2013). The loss is severe and the consequence can be relentless. Parents who suffer from PTSD related to the illness and death of an infant or child are often co-diagnosed with depression, cancer, type 2 diabetes, psychiatric instability, suicide, and addiction (Youngblut, Brooten, Cantwell, del Moral, & Totapally, 2013). Such concerns financially and emotionally tax families and social networks even further.

Purpose and Rationale

Infants who survive the NICU experience are at greater risk for negative developmental outcomes, including cognitive delay and additional illnesses, which can serve as triggers to remind parents of the feelings of helplessness and anxiety experienced during the NICU period (Clottey and Dillard, 2013). Avoidance and attachment concerns have long-term consequences for children of parents with PTSD including the emotional numbing from PTSD impacting the quality of necessary bonding (Clottey and Dillard, 2013). Furthermore, parents of infants in the NICU suffer from deterioration of their physical and mental health which further isolates them and exacerbates feelings of hopelessness and inadequacy (Bellini, 2009).

There is concern based on observed parental behavior leading to a review of current support. Explored modalities to minimize short and long term parental sequelae include early identification of at-risk parents, effective screening, and promotion of individual trauma counseling. It is established in the literature that PTSD rates in the NICU far surpass expectation, potentially surpassing postpartum depression (PPD) rates themselves (Shaw et al., 2013). Recommendations for screening all mothers, versus mothers considered at risk, are dominating current literature (Shaw et al., 2014a).

Background and Significance

In the United States, experts estimate that 7.7 million people develop PTSD yearly, often experiencing onset of symptoms three to six months after a general trauma (Clottey and Dillard, 2013). Clottey and Dillard (2013) share that the prevalence rate of PTSD following childbirth, in general, ranges from 1.7 to 5.6 %. In a clinical study of 130 NICU parents, 32% of parents had a subclinical stress disorder within 72 hours of childbirth, which evolved into 15% diagnosed with PTSD at day 30 from admission (Clottey and Dillard, 2013).

Posttraumatic Stress Disorder is often associated with service men and women who have returned from war reporting psychological disturbances. However, the American Psychological Association has modified the definition of PTSD to include any situation in which a person had directly experienced, witnessed, or was confronted with an event that involved actual or threatened death or serious injury (Bellini, 2009). Bellini (2009) reminds that extreme events outside the range of usual human experiences elicit psychological responses such as feelings of intense fear, helplessness, or horror. With the birth of a critically ill infant, images of perfection are shattered and worries of death and loss replace the hopes of parents and effect bonding between these parents and their babies (Hatters-Friedman et al., 2013).

Mothers who are unmarried, younger, or with fewer living children tend to express more symptoms of PTSD (Hatters-Friedman et al., 2013). Personality traits considered problematic (such as baseline anxiety, ineffective coping, or distrust), postpartum psychosis, or other serious mental health illnesses also predispose a parent to PTSD (Hatters-Friedman et al., 2013).

Mothers with elevated postpartum depressive symptoms or those similar to PTSD are less responsive to their infants' needs and engage in fewer social behaviors towards their infants

resulting in fewer mother-infant interactions (Garfield et al., 2015). Garfield et al. (2015) state that mothers with elevated symptomology of PTSD have been linked with infant failure to thrive, increased risk for developmental delay, and difficulty with social interactions. Consequences of an early NICU encounter continue into adulthood with increased rates of hospitalization and chronic illnesses; thus ease of parental emotional stress is not expected (Garfield et al., 2015). Unfortunately, parental symptoms of PTSD place an infant at even greater risk for altered growth and development compared to infants with non-symptomatic parents (Garfield et al., 2015).

Holditch-Davis et al. (2016) state that infants in the NICU who experience severe illness produce parents with extreme anxiety scores versus those less ill. Within the authors' study, the parents who reflected extreme anxiety during their NICU stay were the parents who remained at risk of significant psychological distress one year after discharge creating a less-positive perception of the infant (Holditch-Davis et al., 2016). Perception of the infant and the infant's capability to fulfill social norms is imperative for some parents and their ability to bond. It could be argued that a variety of factors alter parental perception including social milestones, cultural expectation, and personal desire for the infant to fulfill familial norms (Holditch-Davis et al., 2016).

Shaw, Bernard, Storfer-Isser, Rhine, and Horwitz (2013) unexpectedly found a positive correlation between parental education and the symptomology of PTSD. The authors infer that highly educated women are found to be experts with problem-focused coping and the failure of this approach in the NICU, where very little is under their control, which sets them up for a heighted sense of failure and negative self-appraisal (Shaw et al., 2013). Furthermore, Shaw et al. (2013) question if an advanced education relates to a solid understanding of potential long term developmental issues, therefore creating a more realistic sense of impairment.

Timely recognition of symptoms is critical although easy to miss as parents are engrossed in the newborn's needs. The need for a NICU admission places considerable emotional, psychological, and financial burden on parents, families, health care resources, and society (Lasiuk, Comeau, & Newburn, 2013). Typically, costs are estimated that relate to inpatient and follow-up care, but non-financial costs such as adverse psychological/emotional effects, family disruption, relationship strain, alteration in self-esteem, and deterioration of physical and mental health have not been considered (Lasiuk, Comeau, & Newburn, 2013).

Internal Evidence

Within a 32 bed NICU contained within a children's hospital in the southwestern United States, significant levels of suspected PTSD and mal-attachment are noted. Often, parents are not involved with their infant's care, do not visit or call for updates, and do not provide breastmilk or care supplies for their baby. Parents are missing appointments for medical training and care conferences with the medical team and refusing to accept the infant upon discharge. Post-discharge, the facility's NICU follow up team has noted that medical appointments are being missed and readmission rates related to acquired community illnesses and failure to thrive rates are higher in families who displayed signs of PTSD in the NICU (T. Bullock, personal communication, June 15, 2016). Additionally, parents are verbalizing that they feel ill-prepared to care for their infant, both emotionally and physically, at discharge (T. Binger, personal communication, August 1, 2016).

This unit admits patients who have proved themselves critically ill in another NICU and now require advanced levels of care. Therefore, these infants and families are already at a higher risk for mal-attachment as well as both short and long-term chronic illness sequelae. Current evidence suggests that an infant's medical condition can become more complicated by a mal-

attached parent (Hatters Friedman et al, 2013). As a parent's emotional security becomes compromised, they tend to distance themselves from the infant and refuse to engage in techniques known to strengthen an infant's ability to recover more rapidly. These techniques include holding the infant skin-to-skin or pumping breast milk, both known to reduce the incidence of compounding diagnoses, such as bronchopulmonary dysplasia or necrotizing enterocolitis (Furman & Kennell, 2000).

With nearly 80% of parental samples positively screening for symptoms of depression, anxiety, and trauma within the first few days of the NICU admission (Shaw et al., 2014a), intervention and support must be considered. The data has led to a clinically relevant PICOT question: In parents who have a newborn in the neonatal intensive care unit, would implementation of individual trauma counseling rather than current clinical practice reduce the incidence of post-traumatic stress disorder at discharge.

Search Strategy

With the intention to answer the afore mentioned PICOT question, the databases used for the literature review included Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed (Medline), and ERIC (ProQuest). The initial search strategy included the keywords *NICU, PTSD, posttraumatic stress disorder*, and *neonatal*. Both American and English spellings of keywords were used. Filters were set to published date within the last five years. The Boolean connector "and" was utilized.

An initial CINAHL search rendered four resources using the search terms *stress disorder* and *NICU* which was modified by changing the filter to only include publication dates within the last five years. That modified search tapered the amount to two articles. In an attempt to foster a larger yield, the acronym *PTSD* was substituted for the full term *posttraumatic stress disorder*

which provided one additional article (now three). The acronym *NICU* was replaced with a broad term, *neonatal*, offering the inquiry a final yield of six (Appendix A).

An initial PubMed search rendered thirty-one resources with the search terms *NICU* and *PTSD*. However, with the filter adjusted to publications dates within the last five years, a final yield of seventeen was accomplished (Appendix B).

Finally, an advanced search with ERIC using the search terms *NICU AND PTSD* displayed no results (Appendix C). All search terms mentioned were entered into the search field without gain.

Exclusion criteria included published dates prior to 2012, those written in non-English language, or those that lacked scholarly scaffolding (editorial tone or low level of evidence). Most of the studies were done in the United States, which limits the demographics, therefore limiting study findings as the results may not necessarily translate to other populations. Of the studies meeting inclusion criteria, several were discarded related to obvious flaws in methodology, ethical considerations not being upheld, poor documentation, lack of disclosing funding, or incomplete statistical analysis. After critical appraisal of remaining resources, ten were selected for inclusion within this literature review. Those chosen soundly evaluated the relationship between parental symptoms of stress and anxiety (PTSD) and the neonatal intensive care unit (NICU) as well as various methods proven to minimize symptoms of mental health insecurity in NICU parents.

Critical Appraisal and Synthesis

Upon completion, 10 studies were chosen for inclusion using rapid critical appraisal (Appendix D). The final studies selected were mainly conducted in the United States, except for one which was performed in Poland. This limits the study findings, as the results may not

necessarily translate to other cultures or populations. Validity and reliability is universally suggested as standardized instruments were utilized. The literature reviewed consisted of samples derived from typical NICU populations; however, not all families agreed to participate. This created a bias with the suggestion that parents who could be more at risk for PTSD refused to participate in research or could not handle further emotional intrusion. Furthermore, the studies demonstrated a moderate degree of homogeneity, as most were women versus men and of childbearing age. The literature reviews (two) and meta-analysis (one) presented with a bias tone and lacked validity, whereas the survey trials (six) and randomized controlled trial (one) provided more depth and power but appeared assumptive. In addition, small sample sizes or insufficient amounts of references were used (Appendix D). All studies failed to define a conceptual framework to guide their work, forcing inference.

Sample sizes ranged from 21 to 249 participants, with very similar inclusion and exclusion criteria. Every study was performed in a Neonatal Care Unit and one followed families into the community. All of the studies were initiatives of NICUs affiliated with academic institutions, such as Lucille Packard Children's Hospital: Stanford. Study lengths varied from three to 13 months.

The most common outcomes spoke of the need to screen parents for PTSD in eight out of 10 authors (Appendix D). Secondarily, the need to foster the bedside parental role was consistently revealed in 60% of the studies (Appendix D). The use of bringing mental health providers to the bedside was a recurring theme (Appendix D).

Conclusions of Literature Review

Research evidence overall supports the finding that screening all parents for PTSD is crucial in the NICU (Appendix E). Hypotheses related to potentially more at risk parents (for

example, more versus less educated) do not present consistently, therefore all variables and demographics must be considered. Fostering the parental role in the NICU empowers the family, thereby reducing symptoms of PTSD. A reduction in the severity of parental PTSD promotes the overall health of the parent and the infant, short and long-term. Role empowerment can occur via a variety of methods, including addressing the psychosocial well-being of the parent (Appendix E).

Contribution of Theory

Moos & Schaefer's Conceptual Model for Understanding Life Crises and Transition (Moos & Schaefer, 1984) (Appendix F) organizes the concept of life crisis and transition. According to the framework, the environment and personal systems jointly affect the likelihood and severity of life crisis and the ability to transition. The personal system includes sociodemographic and personal resources such as cognitive ability, health status, motivation and self-efficacy. Life crises or transitions reflect changes in ongoing personal factors such as illness or environmental factors such as death. Clearly, this conceptual framework supports the ties between parents of critically ill newborns in the NICU and posttraumatic stress disorder highlighting the need to transition oneself through stress and environmental factors (i.e., preterm birth) with the use of personal and environmental resources (i.e., nursing direction to develop modified parental role).

Evidence Based Practice

The model chosen to guide the application of the synthesized evidence is the Model for Evidence-Based Practice Change (Rosswurm & Larrabee, 1999). The tremendous advances in clinical research and accessibility to research findings have created a shift in the paradigm from traditional practice to an expectation of evidence-based care. This model illustrates the process

for implementing research evidence into clinical practice in six specific steps (Appendix G). These steps will guide the planning of implementation and evaluation of the project. Rosswurm and Larrabee's model is based on theoretical as well as research literature. Evidence-based practice, research utilization, standard language, and change theory drive the framework. The model is supportive of practice change derived from a combination of qualitative and quantitative data, contextual evidence, and clinical expertise.

This model speaks to the idea of integration versus replacement. It's important to hold close to our past while modifying our future. Parents have been subjected to the NICU for decades with hundreds of thousands of successful stories and illustration that supportive techniques have minimized the effect of trauma. Research needs to practice modification of workable systems based on evidence. This model allows for the emotional variance expected with regards to human behavior.

Application of Evidence to Practice

Following the six steps of Rosswurm and Larrabee's Model for Evidence-Based Practice Change, a pilot program was implemented into the 32-bed neonatal intensive care unit. This occurred after the careful investigation and approval of the facility's Internal Review Board. The parents with infants admitted to the unit who were deemed at risk via the facility social worker or medical team were offered program inclusion. At discharge, the participants were approached to participate in an analysis of efficacy via self-disclosing questionnaires. Minimal demographics and data were obtained by personal interview, such as: infant's age at admission, participant's self-disclosed support system, any history of mental health, and the severity of the infant's diagnosis. Stakeholders included the administration of the pediatric facility, the neonatal medical director, the NICU's manager, the NICU's social worker, facility social work manager,

and the facility's psychiatric department. Additional stakeholders included the advanced practice nursing student, the patients, the parents, and the nursing and medical team program champions. Furthermore, community-based organizations who have historically followed NICU parents outpatient, from a mental health standpoint, have been awarded grant money to offer post-discharge trauma counseling.

Upon admission, participants deemed at risk by the facility social worker or medical team were offered counseling services by a licensed marriage and family therapist specially trained in trauma. A consultation was ordered and the counselor approached the family members at the infant's bedside or by phone call one afternoon per week. Over the course of their infant's stay, the families who chose to participate in the parental psychosocial support program were closely monitored and supported. At discharge, a neonatal anxiety scoring tool (PSS: NICU) (Appendix H) and a parent satisfaction scoring tool (NIPS) (Appendix I) were utilized to compare the scores of cohorts of cumulative time counseled. Counseling not only supported the trauma and grief/loss needs of the participant, but also empowered the parent role by encouraging the learning of how to hold their critically ill infant skin-to-skin despite necessary respiratory support, diaper and bathe their infant despite central lines and equipment, and make choices for their baby's care. Participants were also encouraged to scrapbook, journal their infant's milestones for the national Beads of Courage program (Beads of Courage, 2017), participate in non-nutritive nuzzling, and attend weekly care conferences with the infant's multidisciplinary team. Extensive diagnoses education was assured by program champions who utilized the facility's patient medical library. Effective discharge expectations and teaching were maintained by nursing and case management throughout the NICU stay. All disciplines of the NICU exhausted efforts to update and include families in care treatments or therapies. The

participants' needs and progress were monitored on a weekly basis, including active sources of dissatisfaction and barriers to developing their optimal parental role as modified by the NICU course.

Data Collection and Analysis/Outcomes

As per facility permission, the first 20 participants (*n*=20) of the pilot counseling program were approached at their infant's bedside on day of discharge. They were made aware of the trial nature of the counseling they participated in and asked to, at their leisure, engage in a review process of how they felt they benefitted from the counselor, if at all, and what service modifications could be made to better serve facility families moving forward. They were asked to complete 5-point Likert scale questionnaires, the NIPS and PSS:NICU, each consuming approximately 10 minutes of their time. The participants were made aware that no chart review would occur, no HIPPA data would be collected or shared, and that their answers to questions and any shared comments would remain anonymous. The 20 referrals were shared with the investigator via the facility counselor following the family once discharge was pending within the next 48 hours. An informal process of program review and suggestions occurred for approximately 15 minutes. The family was left with the facility approved NIPS and PSS:NICU questionnaires for another 15 minutes at which time the investigator returned to answer questions and gather the unidentified data. The questionnaires were labeled at that time with a participant ID of one thru 20. The unidentified data was transferred via investigator into a password protected SPSS data spreadsheet and discarded in the facility's privacy protected receptacles.

Upon analysis, a mean facility admission occurred at or on 19 days of patient life, although 50% of the admissions occurred on the first day of life. Seventy percent of participants referred to family as a source of support rather than nurses or faith and 30% reported a mental

health history. Sixty-five percent of participants stated an outstanding relationship with the facility in which their baby was born. Fifty-five percent of participants claimed their infant will suffer from severe long-term needs or there is an expectation of death (Appendix J). Fifty percent (n=10) of participants self-reported receiving five to seven hours of counseling, with the other fifty percent creating an equal distribution curve, maintaining a well-represented population sample.

Overall, 85% of parents stated they were satisfied with the care their infant received (Appendix K) and 95% would recommend the facility to another parent (Appendix L). Seventy-five percent of participants stated they were unsure who to trust with their infant's care (Appendix M). The care satisfaction scores revealed a positive correlation between greater exposure to counseling and higher satisfaction scores (Appendix N). Two groups were created for hours counseled: those participants who were counseled up to four hours and those who were counseled five or more. A null hypothesis stated that both groups would demonstrate the same satisfaction score. An alternative hypothesis stated that they would not have similar satisfaction scores, with an alpha (p-value) greater than 0.05. The null hypothesis was rejected ($p= 0.07$) (Appendix O).

However, there was not a reduction in overall anxiety scores related to hours spent counseled. Amongst the PSS: NICU anxiety scoring tool questions, a statistical shift related to counseling was not consistently seen. Despite the number of hours counseled, parents persistently expressed their feelings of helplessness (Appendix P). Forty-five percent of participants perceived errors had been made in their infant's care (Appendix Q). High self-reported anxiety scores persisted at 65 to 75% of participants despite hours counseled (Appendix R).

The families shared program feedback with the investigator during the interview process. Many trends, despite power, were noted overall. The concerns expressed about a participant's NICU stay included feeling intentionally disempowered by the nursing staff, not feeling supported to breastfeed or hold their infant when they chose, personal comments were overheard about their baby (size, smells, outcomes, abilities), and primary nursing not being adhered to related to staffing needs. Additionally, participants stated inconsistencies with what was being communicated to them regarding their infant's care methods, diagnosis, possible outcomes, need for labs and diagnostics, and what appeared as a lack of communication between the specialists and neonatologist. Participants shared concern that logistical supports were not well met, stating that accommodations posed a challenge, multiples were separated, their infant's room kept changing, and the discharge felt hurried. They also mentioned the inaccessibility of the infant for family members, having to wait in lobby for unit closures, and not being updated by the infant's doctor often enough.

Furthermore, overstimulation was often expressed by the participants, commenting on bright and noisy monitors and pumps, loud personal conversations by the staff (lack of professional behavior, political in nature), the large number of nurses and doctors they met, and lack of sensitivity and reverence for the environment (loud, inappropriate, short with family when answering a question). Lastly, perceived lack of transparency was highlighted. Participants expressed concern over situations such as being called into a care conference without being told the nature of the conversation and a lack of representation from all facets of care during team decision making processes.

However, participants stated that, despite errors (reported occurrence rate of 45%), team transparency was appreciated and apologies to the parents were made. Attempts to correct the

error or make the situation right eased participant concerns. Participants reported trusting the community reputation of the facility and that the NICU and the medical staff lived up to their expectations as staff was open to questions and teaching the family how to care for their infant.

Implications

At discharge, the participants participated in an informal verbal interview that investigated satisfaction and stress. They completed two screening tools: 1) to measure levels of PTSD and associated anxiety (PSS: NICU) and 2) to measure parent satisfaction with medical care in the NICU (NIPS). It was predicted that fostering attachment by supporting the psychosocial needs of the parents would minimize PTSD symptomology and, in turn, offer improved neonatal health outcomes, shortened lengths-of-stay, and efficient discharge planning. It could be stated that financial savings would be favored by private insurance companies, state and federally funded low-income insurance programs (such as AHCCCS), and this facility that operates under budget constraints related to noninsured or underinsured patient populations. Furthermore, facilities such as this are driven by patient satisfaction surveys as well as fostering trusting bonds in a disputative culture. It is often noted that parents who feel engaged and empowered tend to cooperate with their infant's care team and adhere to timely decision making regarding the infant's care.

Evidence supports the idea that role fostering typically minimizes social strain at discharge. The parent finds it easier to resume previous social contributions and relationships. Furthermore, parents who suffer less stress in the NICU related to role promotion and emotional support report a reduction in physical ailments and mental health compromise (Aftyka, Rybojad, Rozalska-Walaszek, Rzoñca, & Humeniuk, 2014). Additionally, with the implementation of a successful program, data shows that infants are less likely to succumb to developmental delay

associated with lack of environmental stimuli or lack of parental engagement with follow up therapy or medical plans (Hatters-Friedman et al., 2013). This potentially lessens the burden on state neonatal intensive care follow up programs and school districts.

However, with this analysis, demonstration of statistical significance was not achieved. Inference to the general population cannot be stated. This could be related to the small sample size (*n*=20). Facility satisfaction scores were reflective of emotional support hours spent but anxiety scores remained unchanged. This could be attributed to the severity of illness seen in this NICU where, tragically, more than half of parents expect their infants to sustain severe long term needs or die (Appendix J). Thirty percent of this sample stated baseline mental health concerns (Appendix J). Therefore, it's possible that generalized evidence-based literature cannot be inferred to a NICU where parents see greater levels of stress and anxiety or have a higher predominance of mental health concerns at baseline.

Plan for Sustainability

This analysis consisted of reviewing the efficacy of a trial counseling program for the NICU families in a Southwestern pediatric facility. Per positive feedback from the participants, nursing staff, and overall improved success demonstrated by the NICU families, the program will be maintained in the NICU. Long term funding has been approved through the facility's Department of Psychiatry. It has also been implemented into the Fetal Care Clinic where families will meet with the counselor prior to delivery and have pre-trauma assessments in order to improve methods of service.

While reviewing the program with participants, it was determined that accessibility to the counselor was a concern. She was only in the NICU one afternoon per week and the participants felt this was not a sufficient amount of time. They did not have any contact method for her and

could not schedule appointments. The random unit sweeps would not always catch all participants requiring assistance. Per participant recommendation, a text or page option would have served them well. Nurses stated they would be agreeable to creating referrals for families they feel are at risk (confirmed scope of practice) and would also be willing to use the facility's real-time paging service (Vocera) to request mental health services to the infant's bedside. Participants verbalized a desire to engage in technical methods of support, such as utilizing the facility's app-based program for patient information. It was recommended that an app-based mental health resource be implemented to the patient portal including easy to read information on posttraumatic stress disorder in the NICU and ways to care for themselves as parents. Participants suggested a group-based support method that would allow for personal connection and support and relationship building for long-term resource development. With 70% of participants stating their family is their main source of support, additional methods to support family involvement should be investigated.

Participants offered positive feedback on methods currently being utilized by the facility to support their mental health and ease the stress of their NICU journey including infant video cameras, shift-to-shift text-option care satisfaction surveys (green thumbs up versus red thumbs down with clinical supervisor follow-up), medical director and unit manager rounds once a week to address concerns and satisfaction, primary nursing, and weekly multidisciplinary rounds inclusive of families.

With the preliminary data, input from the participants and program staffers, as well as innovative facility goals, program reanalysis should be considered once the modifications have been made. For research power and statistical significance, a larger sample size should be utilized. Alternative methods to assess a participant's mental health baseline and supportive care

needs should be sought. Recommendations for further research would include ways to minimize overstimulation in the NICU, education related to staff biases and supportive language, parental sleep rooms conjoined with NICU patients, and skin-to-skin holding involving all family members.

Dissemination of Project Findings

Per facility request, analysis findings will be presented to the Family Advisory Committee. It is expected that the NICU medical director, NICU manager, facility Chief Nursing Officer, NICU Developmental Specialist, NICU social worker, NICU Counselor, and Nurse Champions for the trial program will be present for the presentation. Data and suggestions will be shared with the counselor, privately, prior to the unit presentation to allow for program remodeling and feedback in a private setting.

The project poster will be displayed at the facility's Research Day amongst other research projects that have been completed by medical staff for the current year. The poster will then be displayed in a staff-visible location within the NICU and an educational email rollout will occur via the facility's educator. Application to topic-related conferences will occur over the following one to two years with a goal to share the importance of minimizing parental emotional strain in the NICU and possibly reducing the rates of PTSD, nationally. The disseminatable data will be presented in poster and/or power point form. Submission for publication will occur with highly esteemed journals such as American Academy of Pediatrics, American Journal of Nursing, or Journal of American Academy of Child & Adolescent Psychiatry.

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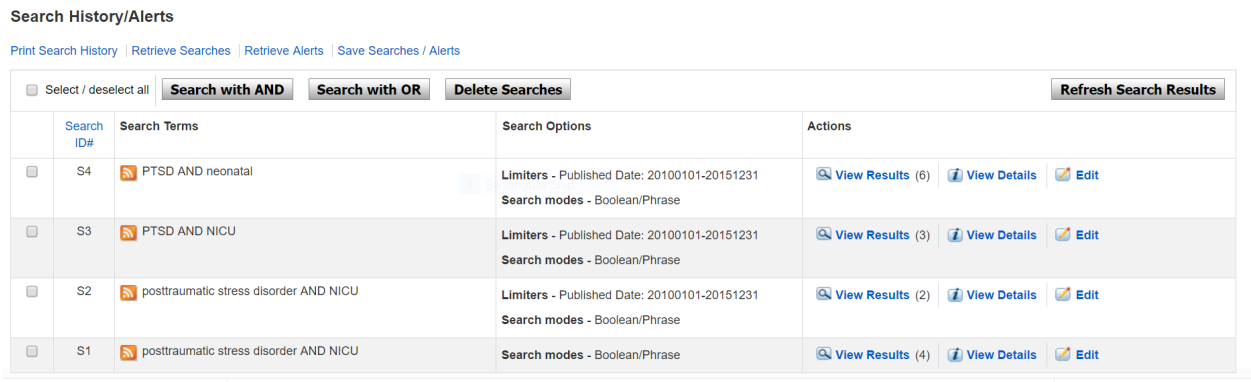
Shaw, R. J., St John, N., Lilo, E., Jo, B., Benitz, W., Stevenson, D. K., & Horwitz, S. M. (2014). Prevention of traumatic stress in mothers of preterms: 6-month outcomes. *Pediatrics*, *134*(2), e481-e488. Doi: 10.1542/peds.2014-0529

Youngblut, J. M., Brooten, D., Cantwell, G. P., del Moral, T., & Totapally, B. (2013). Parent health and functioning 13 months after infant or child NICU/PICU death. *Pediatrics*, *132*(5), e1295-e1301. Doi: 10.1542/peds.2013-1194

Appendix A

Search Strategy 1: EBSCOhost CINAHL plus with full text



Search History/Alerts

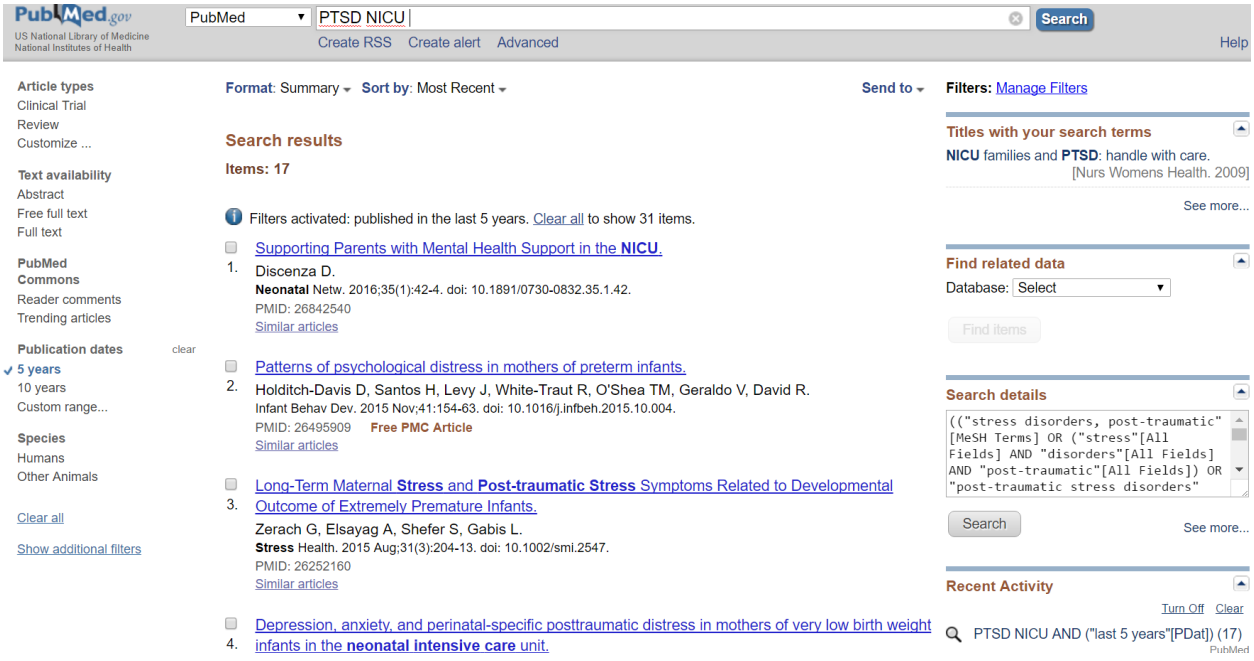
Print Search History | Retrieve Searches | Retrieve Alerts | Save Searches / Alerts

Select / deselect all | Search with AND | Search with OR | Delete Searches | Refresh Search Results

	Search ID#	Search Terms	Search Options	Actions
☐	S4	PTSD AND neonatal	Limiters - Published Date: 20100101-20151231 Search modes - Boolean/Phrase	View Results (6) | View Details | Edit
☐	S3	PTSD AND NICU	Limiters - Published Date: 20100101-20151231 Search modes - Boolean/Phrase	View Results (3) | View Details | Edit
☐	S2	posttraumatic stress disorder AND NICU	Limiters - Published Date: 20100101-20151231 Search modes - Boolean/Phrase	View Results (2) | View Details | Edit
☐	S1	posttraumatic stress disorder AND NICU	Search modes - Boolean/Phrase	View Results (4) | View Details | Edit

Appendix B

Search Strategy 2: PubMed



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US National Library of Medicine
National Institutes of Health

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Article types
Clinical Trial
Review
Customize ...

Text availability
Abstract
Free full text
Full text

PubMed Commons
Reader comments
Trending articles

Publication dates clear
5 years
10 years
Custom range...

Species
Humans
Other Animals

Clear all

Show additional filters

Format: Summary | Sort by: Most Recent | Send to

Search results

Items: 17

Filters activated: published in the last 5 years. Clear all to show 31 items.

1. Supporting Parents with Mental Health Support in the **NICU**.
Discenza D.
Neonatal Netw. 2016;35(1):42-4. doi: 10.1891/0730-0832.35.1.42.
PMID: 26842540
Similar articles

2. Patterns of psychological distress in mothers of preterm infants.
Holditch-Davis D, Santos H, Levy J, White-Traut R, O'Shea TM, Geraldo V, David R.
Infant Behav Dev. 2015 Nov;41:154-63. doi: 10.1016/j.infbeh.2015.10.004.
PMID: 26495909 **Free PMC Article**
Similar articles

3. Long-Term Maternal **Stress** and **Post-traumatic Stress** Symptoms Related to Developmental Outcome of Extremely Premature Infants.
Zerach G, Elsayag A, Shefer S, Gabis L.
Stress Health. 2015 Aug;31(3):204-13. doi: 10.1002/smi.2547.
PMID: 26252160
Similar articles

4. Depression, anxiety, and perinatal-specific posttraumatic distress in mothers of very low birth weight infants in the **neonatal intensive care** unit.

Filters: Manage Filters

Titles with your search terms
NICU families and **PTSD**: handle with care.
[Nurs Womens Health. 2009]
See more...

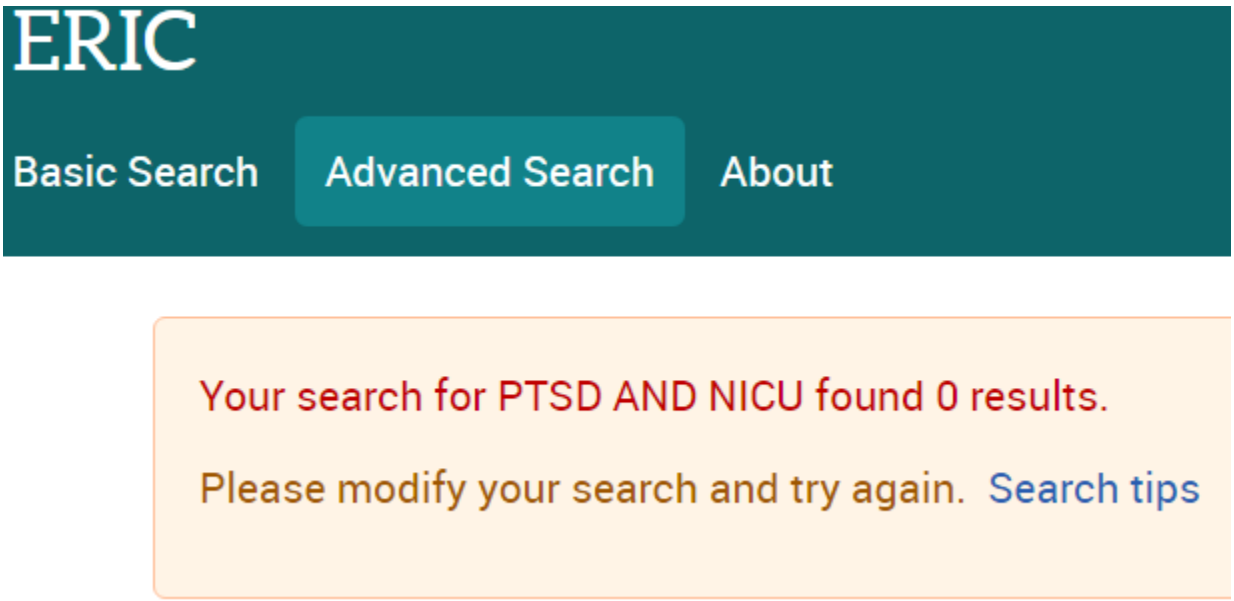
Find related data
Database: Select
Find items

Search details
(("stress disorders, post-traumatic"[MeSH Terms] OR ("stress"[All Fields] AND "disorders"[All Fields] AND "post-traumatic"[All Fields]) OR "post-traumatic stress disorders"
Search
See more...

Recent Activity
Turn Off | Clear
PTSD NICU AND ("last 5 years"[PDat]) (17)
PubMed

Appendix C

Search Strategy 3: ERIC (ProQuest)



Appendix D

Evaluation Table

Citation	Theory/ CF	Design/ Method	Sample/ Setting	Major Variables & Definitions	M/I	Data Analysis	Findings/ Results	Level/ QE Decision
Aftyka (2014) *Post-traumatic stress disorder in parents of children hospitalized in the neonatal intensive care unit (NICU): medical and demographic risk factors* **Funding**: agency **Conflict:** none **Country:** Poland	LCT	**Design:** DST/ Survey **Purpose:** To determine if children of parents diagnosed with PTSD are at high risk?	**N =1** **n**=66 **Demographics:** 39 mothers and 27 fathers of 42 NICU infants ranging in age from 1 to 16 months **Setting:** NICU/ hospital **Inclusions:** ability to read and write Polish, infant in the NICU **Exclusions:** Lack of consent, not legal guardian of NICU infant	**IV:** NICU admission **DV:** Rate of PTSD in parents	Impact of Event Scale-Revised (IES-R) Perceived Stress Scale (PSS-10)	S/10 SPSS 20 MWU	No delta between mothers and fathers and rates of PTSD in the NICU Both elevated Consider causes for PTSD in the NICU	**QE**: 3 **Strengths:** Multiple screening tools used **Weakness**: -small sample size -not a random selection **Decision**: Yes, screen parents for PTSD; implement education or psycho-prophylaxis

Key: **CF** – Conceptual Framework; **Decision**- Decision for practice/ application to practice; **DST** — Descriptive; **DV**-dependent variable; **IV**- independent variable; **LCT** — Conceptual Model for Understanding Life Crises and Transition; **MWU** – Mann-Whitney U-test; N-number of studies; **n**- number of participants; **M/I** - Measurement and Instrumentation; **NICU -**neonatal intensive care unit; **PTSD-**Post-Traumatic Stress Disorder; **QE** – Quality of Evidence; **S/10** – STATISTICA 10 (Statsoft).

Evaluation Table

Citation	Theory/ CF	Design/ Method	Sample/ Setting	Major Variables & Definitions	M/I	Data Analysis	Findings/ Results	Level/ QE Decision
Bellini (2009) *NICU Families and PTSD Handle with Care* **Funding**: Scholarly (University of Connecticut, School of Nursing) **Conflict:** none **Country:** USA	LCT	**Design:** Literature Review **Purpose:** Determine if there is a need for increased awareness related to parental PTSD in the NICU	**Setting:** University of Connecticut, School of Nursing	**IV:** Rate of PTSD **DV:** Increased awareness of parental distress and nursing 27idwest27 ion for NICU parents with PTSD	Not measurable	Review of RCT of N=103 revealed symptoms of PTSD lessened over time (3 mo) with inter-vention	Increased awareness of PTSD can alleviate symptoms	**QE:** 2 **Strengths:** Thorough descriptors such as background on PTSD **Weakness**: Minimal articles used or reviewed; lacked synthesis; sources used lacked large samples **Decision**: Yes, frontline nurses can minimize parental PTSD with active listening and emotion support

Key: **LCT** — Conceptual Model for Understanding Life Crises and Transition; **Decision** — Decision for practice/ application to practice; **DV**-dependent variable; **IV**- independent variable; **LCT** — Conceptual Model for Understanding Life Crises and Transition; **M/I** — Measurement/Instrumentation; **N**-number of studies; **n**- number of participants; **NICU -**neonatal intensive care unit; **PTSD-**Post-Traumatic Stress Disorder; **QE** — Quality of Evidence; SR – Systematic Review; **USA** – United States of America.

Evaluation Table

Citation	Theory / CF	Design/ Method	Sample/ Setting	Major Variables & Definitions	M/I	Data Analysis	Findings/ Results	Level/ QE Decision
Clottey (2013) *Post-traumatic stress Disorder and Neonatal Intensive Care* **Funding**: Scholarly **Conflict:** none **Country:** USA	LCT	**Design:** Literature Review **Purpose** To address the paucity of knowledge related to prevalence, etiology, and PTSD symptoms	**Setting:** Walden University, Tennessee	**IV:** Symptoms of PTSD **DV**: Proper training for NICU healthcare providers	Not measurable Davies (2008) source mentions use of PTSDQ Suggests use of IES; PSS: NICU	Review of RCT (n=211) reveals 3.8% PTSD rates with another 21% with symptom	PTSD is under-recognized and under-reported	**QE**: 3 **Strengths:** Thorough epidemiology and spectrum of parental PTSD detailed **Weakness**: Minimal studies reviewed **Decision**: Yes, lessen trauma for parents in the NICU using empowerment

Key: **CF** – Conceptual Framework; **Decision** – Decision for practice/ application to practice; **DV**-dependent variable; **IES** – Impact of Event Scale; **IV**- independent variable; **LCT** — Conceptual Model for Understanding Life Crises and Transition; **N**-number of studies; **n**- number of participants; **M/I** — Measurement/Instrumentation **NICU** -neonatal intensive care unit; **PTSD-**Post-Traumatic Stress Disorder; **PTSDQ** — Posttraumatic Stress Disorder Questionnaire; **PSS: NICU** – Parental Stressor Scale: NICU; **QE** — Quality of Evidence

Evaluation Table

Citation	Theory / CF	Design/ Method	Sample/ Setting	Major Variables & Definitions	M/I	Data Analysis	Findings/ Results	Level/ QE Decision
Hatters Friedman (2013) *Delivering perinatal psychiatric services in the neonatal intensive care unit* **Funding**: scholarly **Conflict:** none **Country:** USA	LCT	**Design:** Meta-analysis **Purpose:** mothers who would likely benefit from on-site short term psychiatric services in NICU	**N =1** **n**=150 **Setting:** NICU/Hospitals of Cleveland **Demographics:** Two-year period, 150 consecutive referrals to the NICU psychiatrist, included 6 percent of mothers of admitted infants. Mean age 27, typically single, father not usually known, and most employed. **Setting:** NICU/ Hospital **Inclusions:** referral for necessary psychotherapy	**IV:** Psychiatrist present in NICU for readily available therapy **DV:** Rate of PTSD in parents as with mental health symptoms, improved parental functioning, fostering a better parent-child relationship in this high-risk group, and improving the treatment team's morale	REDCap	SPSS Mann-Whitney 60% Unable to cope with infant's illness 43% signs visible depression and anxiety 19% relationship issues 12% on psychotropic meds while infant in the NICU 40% depressed 31% anxiety disorder 5% PTSD 75% accept treatment 56% sought offered therapy	Both at 1 month and 2 years, mothers of VLBW have more psycho-Logical distress than mothers of term infants	**QE:** 3 **Strengths:** Broad demo-graphics **Weakness**: Internal data collection only/retro-spective **Decision:** Yes, having a psychiatrist in the NICU can diagnose parental disorders earlier, facilitate access to care, and better prepare staff

Key: **CF** – Conceptual Framework; **Decision** – Decision for practice/ application to practice; **DV**-dependent variable; **IV**- independent variable; **LCT** — Conceptual Model for Understanding Life Crises and Transition; **M/I** — Measurement/Instrumentation; **N**-number of studies; **n**- number of participants; **NICU** -neonatal intensive care unit; **PTSD-**Post-Traumatic Stress Disorder; **REDCap** – Research Electronic Data Capture **QE** — Quality of Evidence.

Evaluation Table

Citation	Theory/ CF	Design/ Method	Sample/ Setting	Major Variables & Definitions	M/I	Data Analysis	Findings/ Results	Level/ QE Decision
Garfield (2015) *Risk factors for postpartum depressive symptoms in low-income women with very low birth weight infants* **Funding**: Scholarly **Conflict:** none **Country** USA	LCT	**Design:** Descriptive cross-sectional study that was part of a larger RCT **Purpose:** Determine if elevated depressive symptoms are linked to infants with failure to thrive, at higher risk or developmental delays, or have difficulty with social interactions.	**N** =2 **n**=113 **Setting:** Tertiary care NICUs in the Midwest **Inclusion** Mothers of VLBW infants, English speaking, without mental illness, clinically stable infants, no congenital neurological problems. **Exclusion** Mothers younger than 18, ongoing critical illness (HIV), mental health diagnosis, or ventilated mothers.	**IV:** Mothers of VLBW infants **DV:** Higher levels of PTSD symptoms than mothers of infants born greater than 34 weeks gestation	STAI PPQ PSS:NICU CESD NBRS	ANOVA t-tests 30% with PTSD symptoms No difference in symptoms at 1 month or 3 month enroll Worsened symptoms with father living outside of home Low-income mothers experience higher levels of symptoms	Urban, Low income mothers of VLBW infants are at higher risk of PTSD and therefore higher rates of infant illness, parental stress, and re-admits	**QE**: 3 **Strengths:** Numerous measurement tools utilized Mention of IRB approval **Weakness**: Small sample size, urban mothers only, secondary design limited by primary study design and data **Decision**: Yes, screen mothers for factors that predispose them to PTSD (low-income, advanced maternal age, lack of father involvement, and state anxiety) if institutional resources limit screening and care for all mothers.

Key: **CESD** — Center for Epidemiological Studies Depression Scale; **CF** – Conceptual Framework; **Decision** – Decision for practice/ application to practice; **DV**-dependent variable; **IV**- independent variable; **LCT** — Conceptual Model for Understanding Life Crises and Transition; **M/I** — Measurement/Instrumentation; **N**-number of studies; **n**- number of participants; **NBRS** – Neurobiological Risk Score; **NICU -**neonatal intensive care unit**: NICU** – Parental Stressor Scale: NICU; **PPQ** — Perinatal Post-traumatic Stress Disorder Questionnaire; **PTSD-** Post-Traumatic Stress Disorder; **QE** — Quality of Evidence; **STAI** — State-Trait Anxiety Inventory; **VLBW**- very low birth weight.

Evaluation Table

Citation	Theory/ CF	Design/ Method	Sample/ Setting	Major Variables & Definitions	M/I	Data Analysis	Findings/ Results	Level/QE Decision
Holditch-Davis (2015) *Patterns of psychological distress in mothers of preterm infants.* **Funding**: Scholarly **Conflict:** none **Country:** USA	LCT	**Design** RCT **Purpose:** To determine if mothers with high depressive scale indicators remain at risk one year after their NICU stay	**N =2** **n**=232 **Demo-graphics:** Race, first time mother, age, married, PA, data on infant **Setting:** 4NICUs-Two southwest region and two Midwest regions **Inclusions:** mothers of preterm infants less than 1750 grams, no longer critically ill **Exclusions:** Mothers who did not have custody, infants with substance or neuro issues	**IV:** Mothers stress class membership at enrollment (stress= category) **DV:** Maternal and infant characteristic at enrollment (relationship category)	CESD The Worry Index VCS PPQ PSS: PBC PSS: NICU	Chi Square test F test	Identified subgroups of mothers at risk for PTSD Mothers need to be assessed for patterns of distress, not just based on character-istics	**QE**: 4 **Strengths:** Large sample size, detailed maternal and infant characteristic **Weaknesses:** Class pre-determined; did not ascertain if mental illness prior to NICU admission; ethnic limitations; limit case study time **Decision**: Yes, offers insight into specific sub-groups that are at higher risk for PTSD requiring intervention to ameliorate distress and promote parenting response

Key: **CESD** — Center for Epidemiological Studies Depression Scale; **CF** – Conceptual Framework; **Decision** – Decision for practice/ application to practice; **DV**-dependent variable; **IV**- independent variable; **LCT** — Conceptual Model for Understanding Life Crises and Transition; **M/I** — Measurement/Instrumentation; **N**-number of studies; **n**- number of participants; **NICU -**neonatal intensive care unit; **PA** – Public Assistance; **PPQ —** The perinatal post-traumatic stress symptom questionnaire**; PSS: NICU –** Parental Stressor Scale, NICU**; PSS:PBC** — Parental stress scale: Prematurely born child; **PTSD-**Post-Traumatic Stress Disorder**; QE** — Quality of Evidence; **VCS** — Vulnerable Child Scale.

Evaluation Table

Citation	Theory/ CF	Design/ Method	Sample/ Setting	Major Variables & Definitions	M/I	Data Analysis	Findings/ Results	Level/ QE Decision
Lasiuk (2013) *Unexpected: an interpretive description of parental traumas' associate with preterm birth* **Funding**: Scholarly/ Grant via Alberta Heritage Fund **Conflict:** None vs BioMed Central Ltd **Country:** Canada	LCT	**Design:** Descriptive/ survey **Purpose:** Whether healthcare providers need further education related to the care and referrals needed for mothers of PTB.	**N =1** **n**=21 **Setting:** large western Canadian city **Inclusions:** Caretaker of preterm infant born between 2003-2009; speaks English, provide consent	**IV:** PTB **DV:** Trauma related to prolonged uncertainty	No tool used Phone interview No other methods or analysis shared	No data/ Parental quotes in text Qualitative study	Parental trauma is less related to infant charact-eristics than it is to loss of parental role. Role robbery includes holding, helping care for, protecting from pain, and sharing of the baby with family.	**QE**: 2 **Strengths:** Detailed stories of grief and shock, with parental quotes highlighting the severity of the need for intervention **Weakness**: Small sample size, no use of standardized measuring tool; no true data presented **Decision:** Yes, to promote breast-feeding, kangaroo care, family centered practices, constructing parent role with tangible activities that promote sense of agency.

Key: **CF** – Conceptual Framework; **Decision** – Decision for practice/application to practice; **DV**-dependent variable; **IV**- independent variable; **LCT** — Conceptual Model for Understanding Life Crises and Transition; **M/I** — Measurement/Instrumentation; **N**-number of studies; **n**- number of participants; **NICU -**neonatal intensive care unit; **PTB** – Preterm Birth; **PTSD-**Post-Traumatic Stress Disorder; **QE** — Quality of Evidence.

Evaluation Table

Citation	Theory/ CF	Design/ Method	Sample/ Setting	Major Variables & Definitions	M/I	Data Analysis	Findings/ Results	Level/ QE Decision
Shaw (2013) *Parental Coping in the Neonatal Intensive Care Unit.* **Funding**: Scholarly **Conflict:** none **Country:** USA	LCT	**Design** Descriptive /Survey **Purpose:** Whether DYS parental coping methods effect rates of PTSD	**N =1** **n**=56 **Demographics:** **Setting:** Lucille Packard NICU/Stanford CA **Inclusions:** age 18 years or older, speak English or Spanish, infant was expected to survive, weight over 1,000gram and greater than 37 weeks, transferred to or born at LPCH within 72 hours	**IV:** DYS coping **DV:** Parental PTSD	The Brief COPE SASRQ Davidson Trauma Scale	Chi square Two sample *T*-tests, Pearson correlation ANOVA SAS version 9.2	18% mothers with ASD 30% met criteria for PTSD at 1 month of infant's birth Baseline DYS coping = elevated risk for PTSD Maternal education = increased risk for PTSD (17%)	**QE**: 3 **Strengths:** Numerous screening tools utilized, broad data on subject characteristic and coping styles **Weakness:** Sample size/lacks power, reliance on self-report, Brief COPE tool has not been validated in NICU **Decision:** Yes, support cognitive behavioral interventions that target maladaption and consider all risk factors for therapy (as positive relationship between educational years and PTSD not foreseen).

Key: **ASD**- Acute Stress Disorder; **CF** – Conceptual Framework; **Decision** – Decision for practice/application to practice; **DV**-dependent variable; **DYS –** Dysfunctional; **IV**- independent variable; **LCT** — Conceptual Model for Understanding Life Crises and Transition; **LPCH** – Lucille Packard Children's Hospital; **M/I** — Measurement/Instrumentation; **N**-number of studies; **n**- number of participants; **NICU -**neonatal intensive care unit; **PTSD-**Post-Traumatic Stress Disorder: **SASRQ** — Stanford Acute Stress Reaction Questionnaire; **QE** — Quality of Evidence.

Evaluation Table

Citation	Theory/ CF	Design/ Method	Sample/ Setting	Major Variables & Definitions	M/I	Data Analysis	Findings/ Results	Level/ QE Decision
Shaw (2014) *Screening for symptoms of postpartum traumatic stress in a sample of mothers with preterm infants.* **Funding**: Scholarly **Conflict:** none **Country:** USA	LCT	**Design** Descriptive/ Survey **Purpose** To confirm the suggestion that mothers of infants in the NICU experience considerable psychological distress related to their birth and NICU experience.	**N =1** **n**=135 **Demographics:** Race, first time mother, age, married, PA, data on infant **Setting:** NICU/ Stanford CA **Inclusions:** English or Spanish speaking, infant born between 26 and 34 weeks, weighing over 1000 grams, born or transferred to LPCH within 72 hours	**IV:** PPD **DV:** PPTS	BDI-II BAI SASRQ IHSI REDCap	Two-sample t-test Wilcoxon rank-sum test Chi-square test Fishers exact test ANOVA Kruskal-Wallis test SAS version 9.2	77% screened positive for risk for PTSD or ASD on at least one of the three screens given 47% positive for anxiety 36% positive for depression	**QE:** 3 **Strengths:** inclusion of more than one language, research held at leading neonatal facility, use of numerous screening tools. **Weakness:** Small sample size/limited power for analysis; few single mothers, only screened at 1 week post-admission. **Decision:** Yes, consider PTSD as prevalent as PPD, with potentially longer sequelae and adverse infant outcomes. Maternal Demo-graphics do no offer direction as

								to whom shall be screened and treated; consider universal treatment.

Key: **ASD**- Acute Stress Disorder; **BAI** — The Beck Anxiety Inventory; **BDI-II** — Beck Depression Inventory – Second Edition; **CF** – Conceptual Framework; **Decision** – Decision for practice/application to practice; **DV**- dependent variable; **IHSI –** Illness Health Severity Index; **IV**- independent variable; **LCT** — Conceptual Model for Understanding Life Crises and Transition; **LPCH** – Lucille Packard Children's Hospital**; M/I —** Measurement/Instrumentation; **N**-number of studies; **n**- number of participants; **NICU -**neonatal intensive care unit; **PA** – Public Assistance; **PPD** – Postpartum Depression; **PPTS** – Postpartum Traumatic Stress; **PTSD —** Post-Traumatic Stress Disorder; **REDCap** – Research Electronic Data Capture; **SASRQ** -Standard Acute Stress Reaction Questionnaire; **QE** — Quality of Evidence.

Evaluation Table

Citation	Theory/ CF	Design/ Method	Sample/ Setting	Major Variables & Definitions	M/I	Data Analysis	Findings/ Results	Level/ QE Decision
Youngblut (2013) *Parent health and Functioning 13 months After Infant or Child NICU/PICU death* **Funding**: Scholarly **Conflict:** none **Country:** USA	LCT	**Design** Descriptive /Survey **Purpose** Does the death of a child affect health and functioning long-term (greater than 1 year post death)?	**N =1** **n**=249 **Demo-graphics:** Age, race, education, partnered, income, gender, length of NICU stay **Setting:** Florida Community **Inclusions:** English or Spanish, deceased neonate or child less than 18 years old, and lived at least 2 hours in the NICU/PICU **Exclusion**: Deceased from a multiple gestation pregnancy, foster care placement, or death as result of abuse, etc.	**IV:** Infant or child death **DV1:** Newly diagnosed illnesses such as cancer **DV2:** Divorce **DV3**: Clinical depression **DV5**: PTSD **DV4**: Suicide	BDI IES-R Repeated measures design — at 1, 3, 6, 13 moths post-infant death	ANOVA Post hoc w/ Scheffe and Tamhane T2 tests 176 mothers+ 73 fathers (55 coupled) = 188 families 57% withdrew care 32% failed CPR 11% brain dead	18% did not show health improve-ment over 13 months 32% hospital-ized post death, 28% of which were stress-related. Chronic illness: 108 to 240 132 new diagnoses, including depression angina HTN asthma arthritis. 2 of which were cancer. 1 suicide.	**QE**: 3 **Strengths:** Willingnes to approach and follow bereaved Families, longterm; extensive family character. **Weakness:** 54% response (only those who reply are ready to talk about the death – predispose to healthier outcomes); 79% minority, 35% well educated with income greater than $50,000/yr. **Decision:** Yes, Families w/ experience trauma related to their child experience a twofold rise in health conditions.

Key: **CF** – Conceptual Framework; **BDI** — Beck Depression Inventory; **Decision** – Decision for practice/application to practice; **DV-** dependent variable; **IES-R –** Impact on Events Scale- Revised; **IV-** independent variable; **LCT** — Conceptual Model for Understanding Life Crises and Transition; **M/I —** Measurement/Instrumentation; **N —** number of studies; **n**- number of participants; **NICU —** neonatal intensive care unit; **PICU** – Pediatric Intensive Care Unit; **PTSD-**Post-Traumatic Stress Disorder; **QE** — Quality of Evidence.

Appendix E

Synthesis Table

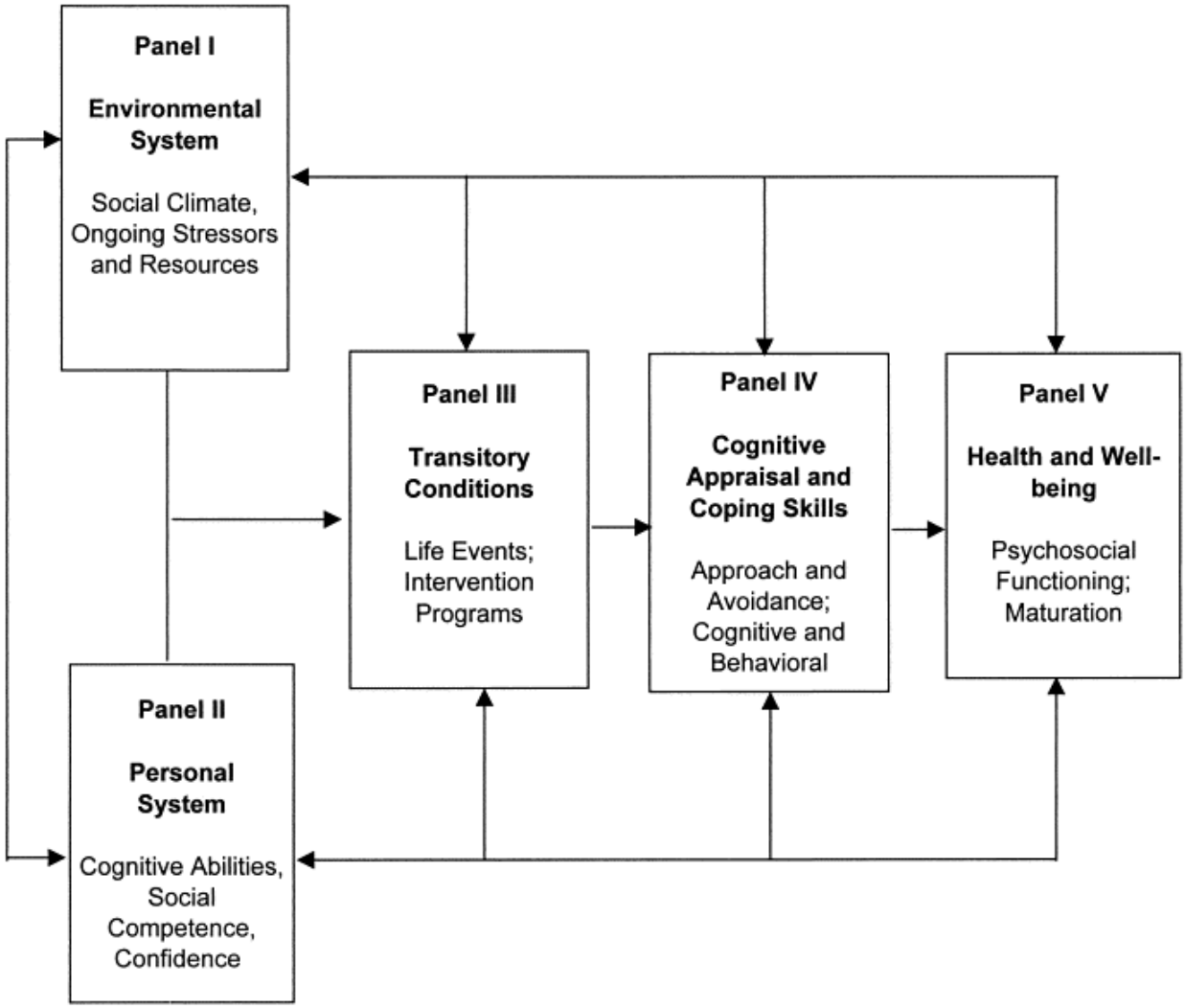
Author	Aftyka	Bellini	Clottey	Garfield	Hatters-Friedman	Holditch-Davis	Lasiuk	Shaw	Shaw	Youngblut
Year	2014	2009	2013	2015	2013	2015	2013	2013	2014	2013
Design	DST	LR	LR	DST	MTA	RCT	DST	DST	DST	DST
Size	66	---	---	113	150	232	21	56	135	249
Setting	NICU	NICU	NICU	NICU	NICU	NICU	NICU	NICU	NICU	COMM
Tool										
BAI									x	
BDI									x	X
CESD				x		x				
COPE								x		
DTS								x		
IES-R	x		(x)							X
IHSI									x	
LR		x	x							
Interview							X			
NBRS				x						
REDCap					X				x	
SASRQ								x	x	
PPQ				x		x				
PTSDQ			(x)							
PSS-10	x									
PSS:NICU			(x)	x		x				
PSS:PBC						x				
SPSS	x				X					
STAI				x						
The Worry Index						x				
VCS						x				
Findings										
Consider all parents high risk	X			x				x	x	
Screening	x		x	x		x	X	x	x	X
Use of LMHP	x	x			X					X
NICU staff aware/create role for parent		X	X	x		x	X	X		
Seek low-income, urban, single, VLBW, MHI mothers				X	X	X				
Advanced Education as risk factor								x		

PPD vs PTSD									X	
PTSD perpetuates physical illness										X

Key: **BAI** — The Beck Anxiety Inventory**; BDI** — Beck Depression Inventory; **CESD** — Center for Epidemiological Studies Depression Scale; **COMM** – Community; **COPE** – The Brief Cope; **DST –** Descriptive/Survey; **DTS** – Davidson Trauma Scale; **IES**-R – Impact of Event Scale — Revised; **IHSI** – Illness Health Severity Index; **LR** – Literature Review; **LMHP** – Licensed Mental Health Provider; **MHI** – Mental Health Issues; **MTA** – Meta-Analysis; **NBRS —** Neuro-biological Risk Score; **NICU** – Neonatal Intensive Care Unit; **PPD** – Postpartum Depression; **PPQ** — Perinatal Post-traumatic Stress Disorder Questionnaire; **PSS-10** — Perceived Stress Scale; **PSS: NICU** – Parental Stressor Scale: NICU; **PSS:PBC** – Parent Stress Scale: Prematurely Born Child; **PTSD** – Posttraumatic Stress Disorder; **PTSDQ** — Posttraumatic Stress Disorder Questionnaire; **RCT** – Randomized Control Trial; **REDCap** – Research Electronic Data Capture; **SASRQ -**Standard Acute Stress Reaction Questionnaire; **SR** – Systematic Review; **STAI —** State-Trait Anxiety Inventory; **VCS** – Vulnerable Child Scale; **VLBW** – Very Low Birth Weight; **X** – main finding; **(x)** – mentions in source.

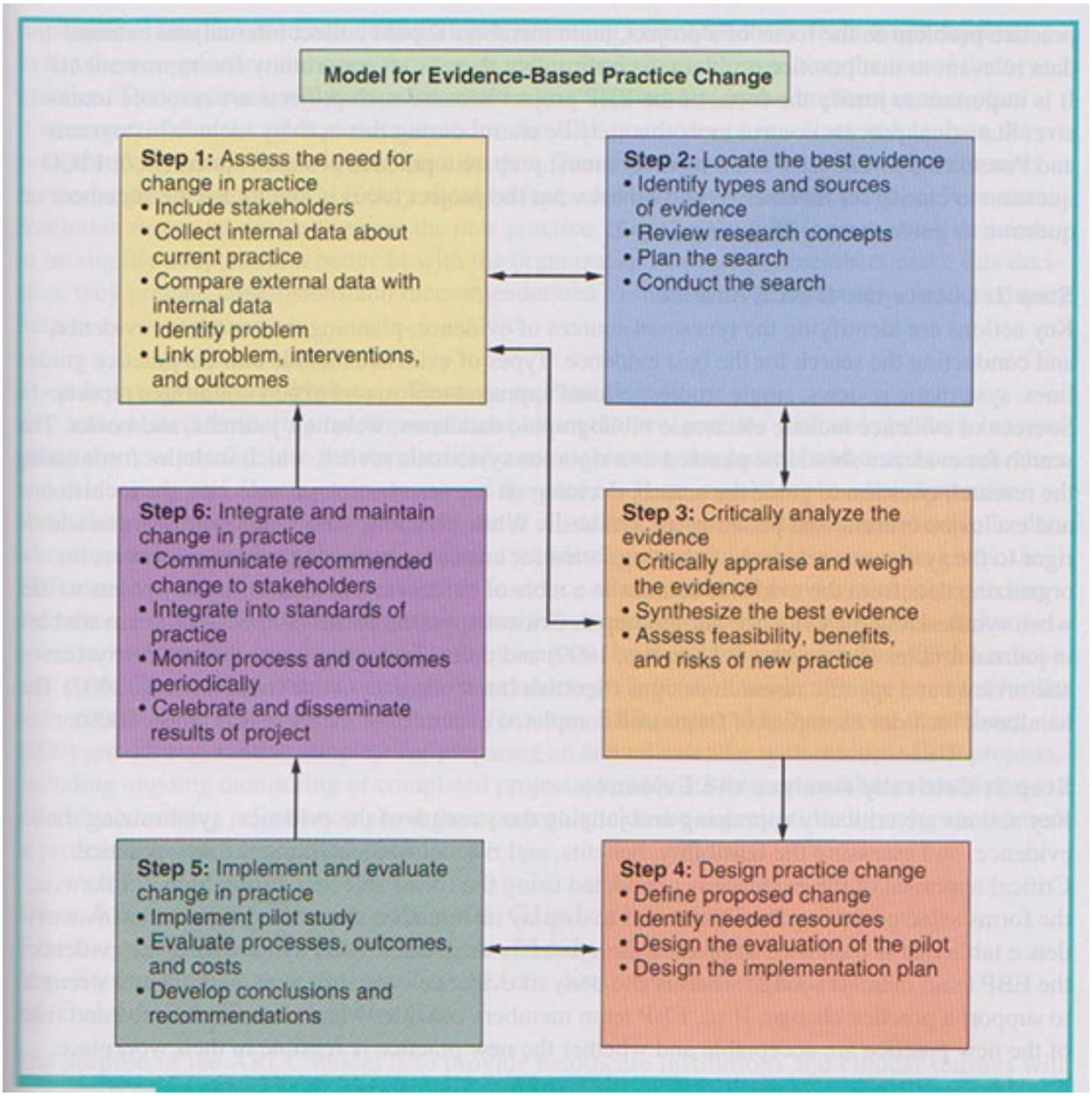
Appendix F

Moos & Schaefer's Conceptual Model for Understanding Life Crises and Transition



Appendix G

Model for Evidence-Based Practice Change (Rosswurm & Larrabee, 1999)



Appendix H

PARENTAL STRESS SCALE: NEONATAL INTENSIVE CARE UNIT

Margaret S. Miles, RN, PhD, Emeritus Professor
Carrington Hall, CB 7460
School of Nursing
University of North Carolina
Chapel Hill, NC 27599-7460
mmiles@email.unc.edu

Copy of Tool
Psychometrics and References
Information for Researchers
Permission Form

2015

PARENTAL STRESS SCALE: NEONATAL INTENSIVE CARE UNIT

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

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

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

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

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

If for example you feel that the bright lights in the neonatal intensive care unit were extremely stressful to you, you would circle the number 5 below:
NA 1 2 3 4 **5**

If you feel that the lights were not stressful at all, you would circle the number 1 below:
NA **1** 2 3 4 5

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

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

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

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

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

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

Thank you for your help.

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

PARENTAL STRESS SCALE: NEONATAL INTENSIVE CARE UNIT

Psychometrics and Scoring

The *Parental Stressor Scale: NICU* (PSS:NICU) was designed to measure the degree of stress experienced by parents during hospitalization related to alterations in their parental role, the appearance and behavior of their child, and sights and sounds of the unit. On the PSS:NICU, parents are asked to rate items on a 5-point rating scale ranging from "not at all stressful" to "extremely stressful."

Data for the original psychometrics of the tool were from a sample of 119 parents (115 mothers and 75 fathers) of premature infants hospitalized in three NICUs located in the 45idwest and southeast United States and one NICU located in Canada. Information about the original psychometrics and scoring can be found in the methodological article: Miles, M.S., Funk, S.G., & Carlson, J. (1993). Parental Stressor Scale: Neonatal Intensive Care Unit. *Nursing Research, 42,* 148-152.

An updated psychometric analysis of the PSS:NICU was conducted with a sample of 128 mothers of at-risk prematurely-born infants in a southeastern NICU (Miles, Holditch-Davis, Schwartz, & Sher, 2007). Factor analysis indicated that the instrument was best conceptualized as having two subscales instead of three. Sights and sounds of the environment (5 items) should be combined with Infant's Appearance subscale (14) and scored as one subscale and Parental Role Alteration remains the second subscale (7 items). Infant's Appearance (Factor I) explained 7.6% of the variance and Parental Role Alteration explained 6.03% of the variance. Cronbach's alpha was .92 for both subscales. In this study, the PSS:NICU longitudinally predicted depressive symptoms in mothers of prematurely-born-children (Miles et al., 2007).

Scoring and Metric Considerations

Parents are asked to rate the stressfulness of each item on the PSS:NICU on a scale from 1 (not at all stressful) to 5 (extremely stressful). However, since parents may not experience every situation—for example, seeing the baby with tubes and equipment on or near him, having the baby's color change suddenly, or having the baby stop breathing—they may indicate N/A (not experienced) on that particular item on the scale. This strengthens the clinical sensitivity of the instrument by providing two possible methods of scoring the stress of parents, the stress occurrence level and the overall level of stress. The "Stress Occurrence Level: (Metric 1) is the level of stress experienced by parents related to their particular situation—in which case only those items they have experienced and rated receive a stress score on the item. The "Overall Stress Level" (Metric 2) is the overall level of stress engendered by the NICU environment—in which case all individuals receive a score on the item, with those not having the experience receiving a "1" indicating no stress was experienced.

For example, if the baby had tubes or equipment on or near him, and the parent rated this as a 3 (moderately stressful) on the stressfulness scale, the parent would receive a 3 by both scoring methods. However, if the baby did not have tubes or equipment on or near him, the parent did not have the experience and would not receive a score by the first scoring method

(Metric 1: Stress Occurrence Level). Using the second scoring method, the parent would receive a score of 1 since this item did not produce any stress (Metric 2: Overall Stress Level).

Subscales

An updated psychometric analysis of the PSS:NICU was conducted with a sample of 128 mothers of at-risk prematurely-born infants in a southeastern NICU (Miles, Holditch-Davis, Schwartz, & Sher, 2007). Factor analysis indicated that the instrument was best conceptualized as having two subscales instead of three. Sights and sounds of the environment (5 items) should be combined with Infant's Appearance subscale (14) and scored as one subscale and Parental Role Alteration remains the second subscale (7 items). Infant's Appearance (Factor I) explained 7.6% of the variance and Parental Role Alteration explained 6.03% of the variance. Cronbach's alpha was .92 for both subscales. In this study, the PSS:NICU longitudinally predicted depressive symptoms in mothers of prematurely-born-children (Miles et al., 2007).

Infant Appearance: Items 1 to 19
Parental Role Alteration: Items 20 to 26

Validity (selected)

In a recent study with data from 177 African American mothers of prematurely-born-children, the correlation between the PSS:NICU subscales and other distress measures was significant and high (Holditch-Davis et al., 2009). For Infant Appearance, the correlation with other distress measures was high: depressive symptoms, .48, posttraumatic stress .49, and state anxiety .39. Even higher correlations were found for Parental Role Alteration: depressive symptoms .56, post traumatic stress .54, and state anxiety .45. The highest distress cluster mothers had significantly higher scores on the Parental Role Alteration Stress subscale.

PSS:Infant Hospitalization

In a study of mothers of medically fragile infants, a slightly edited version of the tool, the *PSS: Infant Hospitalization* was used with 81 mothers (Miles & Brunssen, 2003). The only change was to eliminate items relevant only to preterm infants.
Mean scores on the Parental Role Alteration and Infant Appearance and Behavior subscales were 4.00 or higher and Black mothers had higher scores (Miles, Burchinal, Holditch-Davis Brunssen, & Wilson, 2002). Total scores on the tool were related to both maternal distress and maternal growth (Miles, Holditch-Davis, Burchinal, & Nelson, 1999). Higher scores on the subscale Child's Appearance and Behavior were related to higher levels of maternal worry (Doherty, Miles, & Holditch-Davis, 2002). In a study of correlates of parental role attainment, scores on the Parental Role Alteration subscale of the PSS:IH were related to lower levels of competence, a component of parental role attainment (Miles, Holditch-Davis, Burchinal, & Brunssen, 2011). Please ask for a copy.

International Use

The PSS:NICU is used all over the world and has been translated into many languages, including Spanish, Portuguese, Swedish, Icelandic, Turkish, and Arabic. Due to limited resources, I do not

track or provide copies of translated instruments. These would have to be obtained from the researcher who did the translation. Written permission in the form of an email is requested for any changes an investigator makes to the instrument or to translate into other languages

Permission

You are free to down load or print and use the *Parental Stressor Scale: NICU* for your research. However, the instrument is copyrighted and cannot be duplicated or copied without first returning via email a signed (or indicating your name on the emailed form) permission form including your complete address. If using the instrument only for purposes of a student paper about the tool, no permission is necessary.

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Appendix I

NEONATAL INSTRUMENT OF PARENT SATISFACTION WITH CARE

McMASTER UNIVERSITY

Faculty of Health Sciences

School of Nursing

1200 Main Street West, Hamilton, Ontario, L8N 3Z5

Study ID Number: _____

On behalf of the project team, I would like to thank you for agreeing to participate.

I. How do you think your baby is doing? Would you say that the baby is…

1 DOING BETTER THAN YOU EXPECTED

2 DOING AS WELL AS YOU EXPECTED

3 DOING WORSE THAN YOU EXPECTED

II. This questionnaire has been designed to measure your satisfaction or dissatisfaction with the MEDICAL care your baby has received in the NICU. The MEDICAL caregivers are the neonatologists, nurse practitioners, specialist, and residents. How much contact would you say you have had with the team?

No contact Minimal Some Frequent contact

III. Of these individuals, with whom have you had the MOST contact?

Neonatologist Nurse Practitioner Specialist Resident

FOR ALL THE FOLLOWNG QUESTIONS PLEASE FOCUS ONLY ON YOUR CONTACT WITH THE MEDICAL CAREGIVERS. WE DO NOT WANT YOU TO INCLUDE YOUR CONTACT WITH THE STAFF NURSES.

IV. In general, how satisfied are you with the care your baby has received in the NICU from these MEDICAL caregivers? Would you say you are…

1 NOT REALLY SATISFIED

2 GENERALLY SATISFIED

3 COMPLETELY SATISFIED

1. How often did you find the change of medical caregivers looking after your baby difficult? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

2. How often did these caregivers present your baby's condition in a way which was scary or frightening? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

3. How often did the caregivers fail to tell you when they were going off duty? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

4. How often did the caregivers fail to tell you who was going to fill in while they were off duty? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

5. How often did you feel confused about whom to trust? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

6. How often did you receive conflicting information from different MEDICAL caregivers? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

7. How often did you feel that your baby was lost in the shuffle of a large unit? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

8. How often did you have difficulty finding out who your baby's MEDICAL caregivers were? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

9. How often did you find the change of MEDICAL caregivers over the weekends a problem? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

10. How often did the caregivers fail to inform you about tests or x-ray results? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

11. How often did you have to ask the MEDICAL caregivers to repeat explanations several times? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

12. How often were you uncertain who to talk to about your baby's condition? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

13. How often did the MEDICAL caregivers fail to inform you completely about the results of a procedure? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

14. How often did the caregivers keep you waiting for results of tests? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

15. How often were you informed about something after-the-fact or by accident? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

16. How often did you feel that you knew who was who? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

17. How often did the MEDICAL caregivers volunteer how they felt about your baby's condition? Would you say…

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

18. How often did the MEDICAL caregivers prepare you for your baby's stay in the NICU?

    1. A FAIR BIT OF THE TIME
    2. A LITTLE OF THE TIME
    3. VERY LITTLE OF THE TIME

19. How satisfied were you with the extent to which the caregivers kept you informed as your baby's condition changed? Would you say…

    1. NOT REALLY SATISFIED
    2. GENERALLY SATISFIED
    3. COMPLETELY SATISFIED

20. How satisfied were you with how often the caregivers offered to meet with you in private? Would you say…

    1. NOT REALLY SATISFIED
    2. GENERALLY SATISFIED
    3. COMPLETELY SATISFIED

21. How satisfied were you with the number of meetings arranged with your baby's doctors to discuss what you might expect for your baby in the future? Would you say…

1. NOT REALLY SATISFIED
2. GENERALLY SATISFIED
3. COMPLETELY SATISFIED

22. How satisfied were you with how the MEDICAL caregivers told you about the long-term expectation or outlook for your child? Would you say…

1. NOT REALLY SATISFIED
2. GENERALLY SATISFIED
3. COMPLETELY SATISFIED

23. How satisfied were you with how much the caregivers were sensitive to the other pressures in your life? Would you say…

1. NOT REALLY SATISFIED
2. GENERALLY SATISFIED
3. COMPLETELY SATISFIED

24. How satisfied were you with the extent to which the caregivers offered personal opinions or experiences about your baby's future condition? Would you say…

1. NOT REALLY SATISFIED
2. GENERALLY SATISFIED
3. COMPLETELY SATISFIED

25. Have the MEDICAL caregivers told you when your baby will be discharged from the NICU?

1. YES
2. NO

If yes, how satisfied were you with the MEDICAL caregivers in preparing you for the discharge of your baby? Would you say…

1. NOT REALLY SATISFIED
2. GENERALLY SATISFIED
3. COMPLETELY SATISFIED

26. How satisfied were you with your involvement in the decision to discharge your baby? Would you say…

1. NOT REALLY SATISFIED
2. GENERALLY SATISFIED
3. COMPLETELY SATISFIED

27. How sure were you that your baby's discharge was because the baby was getting better rather than the unit needing the bed?

1. THE NEED FOR A BED PLAYED SOME ROLE IN DECISION
2. MODERATELY SURE BABY WAS READY FOR DISCHARGE
3. TOTALLY SURE BABY WAS READY FOR DISCHARGE

28. Were there times when you thought there were incidents in which errors occurred in the medical care of your baby?

1. YES
2. NO

29. How many times did such incidents occur? _____

30. If your friend was in similar circumstance, would you recommend they come here or go somewhere else for neonatal intensive care?

1. COME HERE
2. GO SOMEWHERE ELSE

Thank you again for taking the time to participate in this project. It is very much appreciated and your answers are very helpful.

Appendix J

Illness Severity

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Concerning	2	10.0	10.0	10.0
	Very Concerning	4	20.0	20.0	30.0
	Critical	3	15.0	15.0	45.0
	Severe long term needs/death expected	11	55.0	55.0	100.0
	Total	20	100.0	100.0	

Mental Health History

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	NO	14	70.0	70.0	70.0
	YES	6	30.0	30.0	100.0
	Total	20	100.0	100.0	

Appendix K

SATOverallCareSatisfaction

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not satisfied	3	15.0	15.0	15.0
	Generally Satisfied	9	45.0	45.0	60.0
	Completely Satisfied	8	40.0	40.0	100.0
	Total	20	100.0	100.0	

Appendix L

SAT Would you recommend a friend hospitalize their baby here

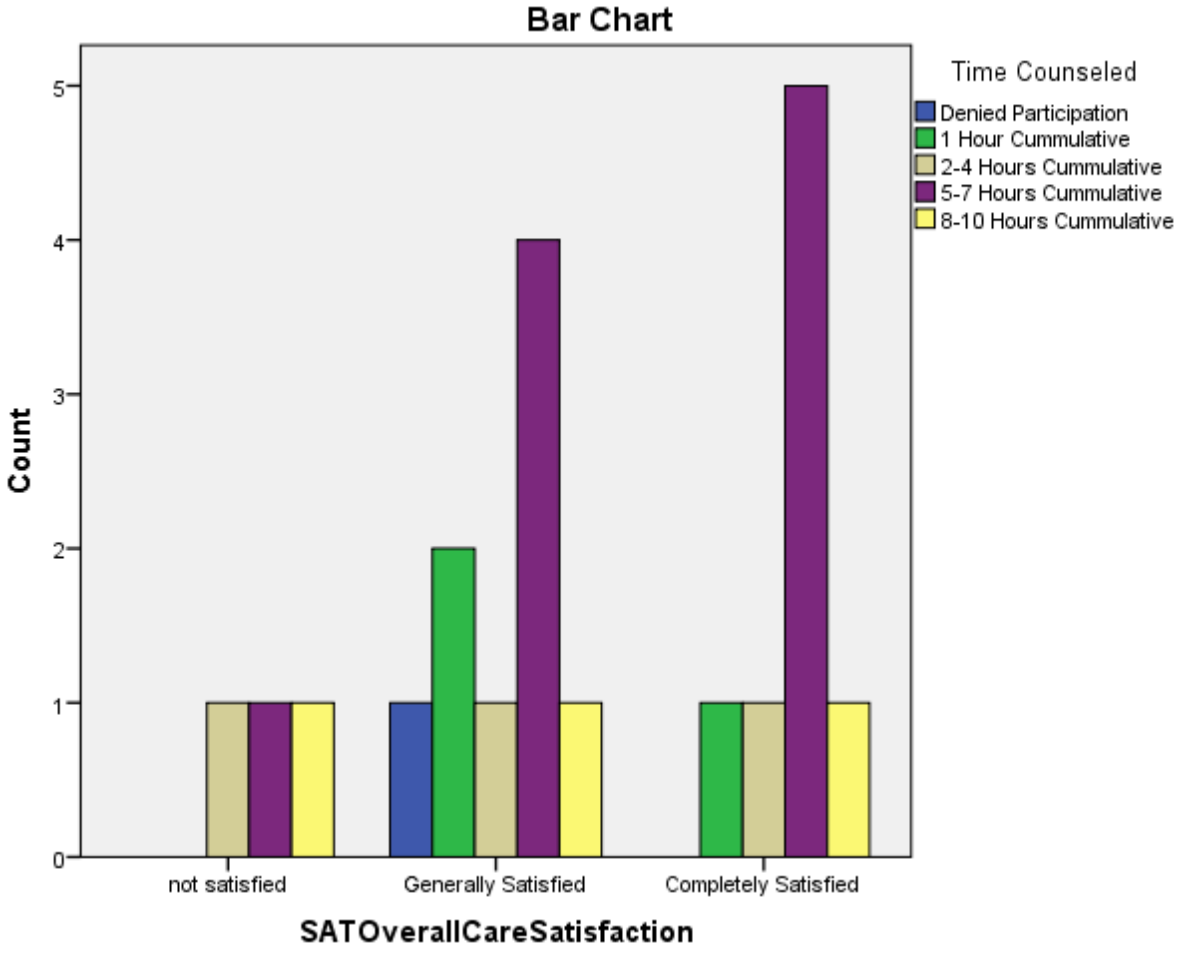
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Come Here	19	95.0	95.0	95.0
	Go somewhere else	1	5.0	5.0	100.0
	Total	20	100.0	100.0	

Appendix M

SAT How often confused who to trust

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	A Fair Bit of the Time	7	35.0	35.0	35.0
	A Little of the Time	8	40.0	40.0	75.0
	Very Little of the Time	5	25.0	25.0	100.0
	Total	20	100.0	100.0	

Appendix N


Bar Chart
Time Counseled
Denied Participation
1 Hour Cummulative
2-4 Hours Cummulative
5-7 Hours Cummulative
8-10 Hours Cummulative
Count
0
1
2
3
4
5
not satisfied
Generally Satisfied
Completely Satisfied
SATOverallCareSatisfaction

Appendix O

Group Statistics

	Counseled Up to 4 hours	N	Mean	Std. Deviation	Std. Error Mean
SATOverallCareSatisfaction	no	13	2.31	.751	.208
	yes	7	2.14	.690	.261

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
CareSatisfacti	Equal variances assumed	.692	.417	.481	18	.636	.165	.343	-.555	.885
	Equal variances not assumed			.494	13.375	.629	.165	.334	-.554	.884

Appendix P

PSS being separated from my baby

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Not at all stressful	3	15.0	15.0	15.0
	Moderately Stressful	2	10.0	10.0	25.0
	Very Stressful	2	10.0	10.0	35.0
	Extremely Stressful	13	65.0	65.0	100.0
	Total	20	100.0	100.0	

PSS feeling helpless and not being able to protect my baby from pain

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Not at all stressful	1	5.0	5.0	5.0
	Moderately Stressful	2	10.0	10.0	15.0
	Very Stressful	2	10.0	10.0	25.0
	Extremely Stressful	15	75.0	75.0	100.0
	Total	20	100.0	100.0	

PSS feeling helpless about how to help my baby

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Not at all stressful	1	5.0	5.0	5.0
	Moderately Stressful	3	15.0	15.0	20.0
	Very Stressful	5	25.0	25.0	45.0
	Extremely Stressful	11	55.0	55.0	100.0
	Total	20	100.0	100.0	

Appendix Q

SAT Were there times you thought errors occurred in your baby's care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	YES	9	45.0	45.0	45.0
	NO	11	55.0	55.0	100.0
	Total	20	100.0	100.0	

Appendix R

Group Statistics

	Counseled 5 hours or more	N	Mean	Std. Deviation	Std. Error Mean
PSS feeling helpless about how to help my baby	no	7	4.4286	.97590	.36886
	yes	13	4.1538	1.14354	.31716
PSS not having time alone with my baby	no	7	2.8571	2.03540	.76931
	yes	13	2.5385	1.19829	.33235
PSS presence of monitors and equipment	no	7	3.0000	1.15470	.43644
	yes	13	3.3846	1.50214	.41662
PSS constant noise of monitors and equipment	no	7	3.0000	1.41421	.53452
	yes	13	3.9231	1.03775	.28782
PSS sudden noises of alarms	no	7	3.2857	1.70434	.64418
	yes	13	4.5385	.77625	.21529
PSS other sick babies in the room	no	7	2.0000	1.73205	.65465
	yes	13	2.4615	1.26592	.35110
PSS large number of people working in the room	no	7	2.1429	1.34519	.50843
	yes	13	2.1538	1.06819	.29626
PSS tubes and equipment on or near my baby	no	7	2.7143	1.11270	.42056
	yes	13	4.2308	.83205	.23077
PSS bruises, cuts, incisions on my baby	no	7	3.0000	1.73205	.65465
	yes	13	3.7692	1.16575	.32332
PSS the unusual color of my baby (pale or jaundiced)	no	7	2.4286	1.61835	.61168
	yes	13	2.7692	1.09193	.30285
PSS baby's unusual breathing patterns	no	7	2.7143	1.25357	.47380
	yes	13	3.6923	1.18213	.32786
PSS the small size of my baby	no	7	2.1429	1.34519	.50843
	yes	13	2.6923	1.54837	.42944
PSS the wrinkled appearance of my baby	no	7	1.2857	.75593	.28571
	yes	13	2.1538	1.34450	.37290
PSS having a machine breathe for my baby	no	7	2.2857	1.88982	.71429
	yes	13	4.2308	1.16575	.32332
PSS seeing needles and tubes put in my baby	no	7	3.1429	1.57359	.59476
	yes	13	4.2308	1.01274	.28088
PSS my baby being fed by an intravenous line or tube	no	7	3.4286	1.51186	.57143
	yes	13	3.1538	1.28103	.35529
PSS when my baby seemed to be in pain	no	7	3.4286	1.81265	.68512
	yes	13	4.2308	1.16575	.32332

PSS when my baby looked sad	no	7	3.2857	2.13809	.80812
	yes	13	3.6923	1.25064	.34687
PSS the limp and weak appearance of my baby	no	7	3.2857	1.70434	.64418
	yes	13	3.9231	1.25576	.34828
PSS jerky or restless movements of my baby	no	7	2.5714	1.51186	.57143
	yes	13	2.9231	1.25576	.34828
PSS my baby not being able to cry like other babies	no	7	2.5714	1.39728	.52812
	yes	13	3.2308	1.42325	.39474
PSS being separated from my baby	no	7	3.7143	1.49603	.56544
	yes	13	4.3077	1.49358	.41424
PSS not feeding my baby myself	no	7	3.7143	1.38013	.52164
	yes	13	3.5385	1.33012	.36891
PSS not being able to care for my baby myself	no	7	3.2857	1.25357	.47380
	yes	13	2.7692	1.36344	.37815
PSS not being able to hold my baby when I want	no	7	3.5714	1.61835	.61168
	yes	13	3.6154	1.66024	.46047
PSS feeling helpless and not being able to protect my baby from pain	no	7	4.7143	.75593	.28571
	yes	13	4.3846	1.19293	.33086