

Promoting Family Centered Care in the Neonatal Intensive Care Unit (NICU)

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Author Note:

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Abstract

While the neonatal intensive care unit (NICU) is often medically necessary, it can contribute significantly to stress for both infants and their families. Weber and Harrison (2019) identifies stress in the NICU to result from the physical environment, the psychosocial environment, and the medical complex requirements. Family centered care has been established as best practice in NICU settings, with increased evidence supporting its positive impact on infants and families (Lee, 2024). This capstone project was conducted in a level III NICU in central Indiana with the goal of enhancing caregiver education to promote greater caregiver participation and to foster a positive healing environment for infants. In collaboration with the site, the student identified a gap between the literature and the practical implementation of family centered care. A mixed-methods data collection approach, including a pre- and post-survey completed by NICU staff, was utilized to evaluate the project's effectiveness. Evidence-based educational resources were developed, supporting a more therapeutic and family-inclusive NICU experience. Project evaluation results indicated a positive impact on caregiver education, staff knowledge, and the student's clinical practice development.

Keywords: neonatal intensive care unit, NICU, family-centered care, positive healing environment, infant, occupational therapy, caregiver education, infant development

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Introduction

The neonatal intensive care unit (NICU) is a specialized area of a hospital that provides treatment to infants in need of intensive medical care. In 2021, 18% of newborns required care from the NICU. The length of stay for an infant in the NICU has large variability, with an average range of 3-34 day (Valencia et al. 2023). Occupational therapy in the neonatal setting focuses heavily on the interactions between caregivers and the infant with an “occupation-based focus on the development of caregiver-infant co-occupations” (AJOT, 2018). This focus develops confidence in caregivers and provides a sense of security for the infant through thorough communication amongst the healthcare team and the infant’s caregivers. This process can be referred to as family centered care.

Family centered care is “the approach that establishes successful partnerships between health care providers and families and can lead to better intervention outcomes for children and families and providers” (Gafni-Lachter & Ben-Sasson, 2022). This approach to care stresses the importance of family and caregivers to the infant’s wellbeing. The core concepts of family centered care consist of respect and dignity, information sharing, participation, and collaboration. Family centered care values a mutually beneficial partnership between the healthcare team, the patient, and the families or caregivers (Institute for Patient and Family Centered Care, n.d.). According to the American Occupational Therapy Association, family centered care is widely recommended as best practice within pediatric occupational therapy. Family centered care is crucial within the neonatal setting to promote the care and well-being of the infant, as well as to meet the needs of the family.

The capstone experience and project described in this paper were completed at a level III NICU in central Indiana. Riley Children’s Health at Indiana University (IU) North contains a

level III NICU to provide skilled care to newborns with urgent medical needs. Despite efforts to improve communication amongst healthcare staff and caregivers, IU North has continued to have difficulty providing consistent and effective education to families throughout their NICU stay. IU North would like to see the development of resources to provide caregiver and hospital staff education in the NICU setting to implement a family care centered approach and to improve continuity of care. This paper outlines the process and results of a 14-week doctoral capstone experience (DCE). The DCE aimed to address facilitation of family centered care in the NICU environment by providing educational materials for NICU families and staff, focusing on optimal healing environments to support growth and development.

Needs Assessment

The Process

The process of developing this capstone began with an interview with a specialized NICU physical therapist at IU North. Due to time constrictions, the interview was conducted via email. Initial questions asked covered base line topics including typical conditions seen at the IU North NICU and what clinical skills past students have been able to gain. Questions then proceeded to discuss the use of family centered care and parent engagement within the facility, as well as what professions are present in the NICU setting and how these professions interact. The largest theme in the answers provided was variability. The variability in family presence, the variability amongst staff communication, and the variability amongst the role of each profession in the NICU were all discussed. The last question addressed gaps that the site has witnessed and experienced within the facility. The response was as follows “Continuity of care, consistency of communication among caregivers and families (especially among float staff)”. This response largely guided the formulation of the capstone purpose. To continue, research was conducted and

reviewed on the best practice within family centered care in the NICU to address the communication between hospital staff and caregivers. Through this research, it was discovered that there is also a connection between the effects of family centered care during a NICU stay and how it effects the continuity of care after discharge.

Gap Analysis

The data presented in the community site profile and gap analysis was collected during an interview with key individuals at the site. The interview served as the primary source of information for understanding the site's needs, structure, and context.

Current State

Riley Children's Health at IU North contains a level III NICU to provide skilled care to newborns with urgent medical needs. The NICU sees a variety of conditions, including congenital abnormalities, neonatal opioid withdrawal, brachial plexus injuries, and prematurity to name a few. A NICU hospital stay can present as an overwhelming and terrifying experience for many caregivers. Proper education is one aspect that can work to reduce the stress placed on these families (Gehl et al., 2020).

IU North and their NICU staff try to adopt family centered care practices, but with each families' situations having such variability, it can be difficult to ensure communication and education among caregivers and families is consistent. Some families live a great distance away and are not able to be present each day. Other families have a caregiver present at all hours of a day. Communication challenges continue to arise due to variability in hospital staff. Unlike hospital staffs' shifts, NICU stays are 24 hours a day 7 days a week. The staff working changes constantly and these patients and families will see multiple nurses and therapists a week, often a day. Additionally, these infants are seeing a variety of types of therapists and physicians. To

ensure the best care for the patients, it is imperative that the medical team provide effective education to caregivers and families.

Desired State

IU North would like to see the development of improved educational resources to provide caregivers and hospital staff in the NICU setting to implement a family care centered approach amongst their entire team. The NICU team can be different depending on the diagnosis or condition of each patient, but often it consists of nurses, techs, speech therapists, physical therapists, and occupational therapists. Improving communication amongst the medical team can result from education to staff members about family centered care principles. This can include educational materials on supportive healing environments, focusing on sensory stimulation and developmental positioning of infants.

Another area that IU North has identified as a gap is the continuum of care of NICU infants. The goal of the NICU is for the infant to have the opportunity to go home with the greatest level of independence with the caregivers. After a NICU stay, it is primarily the caregiver's responsibility to facilitate treatment, transportation, and explanations to the child. The continuum of treatment and recovery cannot be effective without proper communication and education from the medical team to the caregivers. Improving the gap in education from medical staff to caregivers will work to reduce the challenges associated with continuing care after a NICU stay through facilitating caregiver confidence.

Gap

The American Occupational Therapy Association (2020) states that the family centered care in any pediatric occupational therapy setting is the best practice. The core concepts of family centered care consist of respect and dignity, information sharing, participation, and

collaboration (Institute for Patient and Family Centered Care, n.d.). These are principles that each patient and family unit deserve the opportunity to receive when experiencing stay in a NICU. While the NICU at IU North works to implement family centered care in their daily practice, they have found difficulty ensuring consistent caregiver and family education. This presents as a gap between the best practice as identified by current literature and the current practice within this facility. IU North would like to work to bridge the gap to apply family centered care principles through developing resources for caregivers and families to increase quality of education and facilitation of caregiver involvement.

Literature Review

An in-depth literature review was conducted to identify current literature surrounding the neonatal intensive care unit. The information brought increased awareness on the importance of family centered care in the NICU, identifying family-centered care as a best practice in pediatric care. The recent literature was used to present and evaluate the barriers to family centered care in the NICU setting from the caregiver and facility perspective, as well as the carryover of family centered care to continuity of care through discharge to home. The literature identified interventions to reduce stress and encourage caregiver participation to promote development of the infant. The doctoral capstone student utilized PubMed database, Google Scholar, and American Journal of Occupational Therapy (AJOT) to conduct the literature search. The primary search terms included neonatal intensive care unit (NICU), family centered care, positioning, caregiver education, sensory environment, and occupational therapy.

Best Practice: Family Centered Care

Family centered care is a best practice in pediatric occupational therapy (Gafni-Lachter & Ben-Sasson, 2022). The caregivers are the main source of support for a NICU infant and in turn,

parents should be integrated in the plan of care (Simpfronio et al. 2016). In a neonatal setting, infants lack the typical amount of maternal stimulation due to the restriction of being in a NICU. The lack of maternal stimulation can alter emotional development (Gómez-Cantarino S et al. 2020). Bringing the family into the plan of treatment and the administration can contribute to forming a bond between the family and the infant. To bring the family into the administration of care, it is crucial to empower them through establishing a relationship with the health team (Gómez-Cantarino S et al. 2020). Franck et al. (2019) found that increased parental presence allows relationships amongst hospital staff and caregivers to be established, reducing the stress levels, and increasing the sense of safety and control in the parents. Having the caregivers present for consistent periods of time resulted in better adaptation to the external environment for the infant, as shown by improved regulation of vitals. Integrating a family centered care approach promotes caregiver empowerment and learning, as well as a shared decision making amongst the healthcare team and the family. This approach resulted in increased self-efficacy in parents upon discharge and improved infant developmental outcomes (Franck et al. 2020).

Barriers to Family Centered Care

While family centered care has been identified as a best practice in pediatric occupational therapy, it can be challenging to implement consistently and effectively. A qualitative exploratory study interviewed 18 NICU families to determine gaps in family centered care experienced during their time spent in the NICU. Themes present included a lack of mutual trust between caregivers and hospital staff and caregivers feeling a sense of powerlessness. Participants reported feeling judgement from hospital staff regarding ability to be at bedside or feeling disliked by staff (Sigurdson et al. 2020). Family involvement is unique to each situation. Many NICU families are presented with barriers to being able to be at bedside, including location,

finances, and personal responsibilities. It is crucial for NICU staff to show acknowledgement of barriers to build trust and communication with the caregivers to benefit the care of the infant. Similarly, Nist et al. (2024) identified barriers to parent presence at NICU bedside with the two most prominent being home responsibilities and feeling uncomfortable at facilities. Participants in the study reported the greatest facilitator for presence at bedside to be encouragement to participate in care of their infant from healthcare employees. Another qualitative study, “Perceived Barriers of Family Centered Care in Neonatal Intensive Care Units” identified two main themes in barriers: perceived family barriers and perceived facility barriers. The perceived family barriers included stress and anxiety, inadequate information sharing, education, culture, and religion. The perceived facility barriers included inadequate space, staff workload, restricted entry, and negative staff attitudes (Abukari & Schmollgruber, 2024). This study acknowledged the need to incorporate families into the care of their infant but presented the barriers that result in a lack of effective implementation of family centered care values.

Positive Healing Environment

While the NICU is often medically necessary, it contributes to stress levels on the infant and the family system. Weber and Harrison (2019) identifies stress in the NICU to result from the physical environment, the psychosocial environment, and the medical complex requirements. The physical environment consists of overwhelming stressful stimuli including bright lights, heightened noise levels, and noxious smells. Psychosocial stressors arise from reduced positive sensory stimuli due to separation from parents, deprivation of positive touch, and altered response to infant cueing due to constraints of the NICU environment (Weber & Harrison, 2019). Increased stress in infants disrupts the development of the brain by impacting structural connectivity. Family members can be educated to support the infant’s stress signs to reduce

infant stress and encourage a positive healing environment (Howe et. al., 2022). Engagement from caregivers while in the NICU improves parent-infant bonding, creates emotional connections, and leads to development of brain structures and functions (Altimier & Phillips, 2016).

Positioning and Handling

Positioning in the NICU works to facilitate neurodevelopment of the neonate through providing supportive positioning that closely mirrors that of the womb. Developmental positioning is optimal for musculoskeletal development, physiological function and stability, calmness, facilitation of sleep, and brain development (Altimier & Phillips, 2016). Positioning may be used as an evidence-based intervention among healthcare staff, as well as through parent touch and participation. Healthcare staff may provide education to family members to support the infant and reduce infant stress. These interventions can include swaddling, hand containment, keeping the infant flexed, contained, and in midline (Howe et. al., 2022).

Adult Learning Theory

To effectively implement a family centered care approach, it is crucial that NICU staff educate caregivers. Andragogy, also known as “adult learning theory,” is “the method and practice of teaching adults” (Oxford University Press, n.d.). Adult learning theory provides a framework to inform educators on how adults learn best and identifies differences in the learning process for an adult when compared to a child or teenager. Andragogy has been identified as a strong theoretical lens; however, it has yet to be heavily applied to medical and health sciences disciplines. Founder Malcom Knowles promoted the use of adult learning theory throughout healthcare fields due to the frequent changes and updated research (Knapke et al., 2024). When discussing education of caregivers of infants in the NICU, it is crucial to consider the pillars of

adult learning theory. The 6 pillars of andragogy include: the learner's self-concept, the role of experience, readiness to learn, orientation to learning, the learners need to know, and intrinsic motivation (Knapke et al., 2024). To better facilitate caregiver engagement within the NICU, staff can educate caregivers utilizing these principles to better provide education, promote confidence, and create a positive environment and relationship.

Continuity of Care

Family centered care carries high importance in the NICU population as it directly corresponds to the continuity of care of the infant after discharge from the NICU to home. Family centered care sets parents up for success through empowerment and confidence building. A qualitative study, "Parental Perspective on Neonatologist Continuity of Care" analyzed parents' perspectives on continuity of care, identifying valued themes and suggestions for improvement. The four themes identified included: building relationships between clinician and family, background knowledge of the infant condition and history, establishing patient-centered goals, and communication. Strategies for improvement included optimizing transition processes, utilizing clinical guidelines, and improving communication (Machut et al. 2021). The themes identified are a direct carry over of family centered care principles during a NICU stay. Family centered care principles have continued use and importance throughout all pediatric care. Hebballi et al. (2021) explored the challenges families experience when transitioning home from the NICU and identified lack of qualitative parental involvement during the NICU stay as a key barrier to discharge. If caregivers are not involved in care of their infant during their time in the NICU, the caregivers are not developing role competence to carry through discharge. The article's identified areas of improvement were standardization of parental education, improved communication, and support for caregivers' mental and emotional states.

Purpose

In the NICU setting, family centered care is crucial to build confidence and role competency with the caregivers. Family centered care requires mutual communication and trust amongst the healthcare team and the families. While family centered care has been identified as a best practice method, there are substantial barriers present among caregivers and within NICU facilities. Despite efforts to improve communication and education, IU North has continued to have difficulty with consistency and reliability. Due to the site's dedication to implementing family centered care within their NICU, a capstone project focused on furthering the capstone student's clinical skills and education to develop educational resources for caregivers and healthcare staff to promote caregiver participation in the NICU utilizing a family centered care model of practice was completed.

Guiding Theory and Model

Neonatal Integrative Developmental Care Model

The neonatal integrative developmental care model provides a comprehensive neuro-protective family centered approach to care of neonates in the NICU, listing out seven core measures. The seven core measures include (1) healing environment, (2) partnering with families, (3) positioning and handling, (4) safeguarding sleep, (5) minimizing stress and pain, (6) protecting skin, (7) optimizing nutrition (Altimier & Phillips, 2016). The model emphasizes care based on neurodevelopment of gestational age, discussing the neurosensory development of a premature infant in the NICU environment as largely impacted by the NICU staff and family. It addresses the conjunction of development between neurosensory and neurobehavioral systems, guiding the development of educational resources to provide to staff and families on positioning, handling, and positive sensory experiences while in the NICU. The model encourages the

collaboration between hospital staff and families to encourage bonding between parent and infant, further supporting the educational resources to facilitate caregiver participation and confidence.

Capstone Project Plan and Process

Project Plan

The doctoral capstone experience consisted of a 14-week project and on-site experience. Prior to the start of the on-site experience, the student collaborated with the site mentor to establish project goals and objectives that would guide the development of the capstone. Once on site, these goals and objectives were adjusted to better align with the evolving needs of the site. The primary focus of the capstone was to enhance clinical skills in an advanced specialized setting and promote a positive healing environment for infants through the development of educational resources for both hospital staff and families.

Project Goals and Objectives

Project Goal 1: The student will increase their clinical knowledge of occupational therapy in the neonatal intensive care unit (NICU) including diagnoses, interventions, and discharge planning.

Objective 1: The student will work on-site for 80% of the capstone experience in collaboration with the site mentor to develop clinical skills.

Objective 2: The student will receive feedback from the site mentor to continue to develop clinical skill in the pediatric hospital settings of occupational therapy.

Objective 3: The student will observe a developmental NICU follow-up clinic to increase knowledge of long-lasting deficits correlating to prematurity or a NICU stay.

Project Goal 2: The student will improve family involvement in care-plans of their child by utilizing a family centered care lens.

Objective 1: The student will analyze research to determine the barriers to family centered care in pediatric hospital settings.

Objective 2: The student will gather data from hospital staff on gaps in staff competency and educational resources available to families.

Objective 3: The student will utilize the facility feedback to create educational resources for staff and families to improve family involvement and understanding throughout the care of the child.

Project goal 3: The student will facilitate sustainability of the developed project and/or educational resources for the capstone site to utilize and further develop with evolving best practices and needs of the site.

Objective 1: The student will develop and/or organize resources surrounding care in the NICU at the capstone site.

Objective 2: The student will receive feedback from the capstone site staff on the resources developed and organized.

Objective 3: The student will edit resources developed and organized based upon the feedback from the capstone site staff to better suit the needs of the staff.

Project Process

Prior to the on-site experience, the student completed a gap analysis, literature review, and needs assessment to determine the direction for the doctoral capstone project. Upon arrival, the focus shifted toward advancement of clinical skills and the application of findings to refine project development and ensure goals and objectives were met.

Weeks one and two focused on NICU and hospital orientation, including familiarization with medical terminology, diagnoses, the electronic medical record system, and observing

treatment sessions. In week three, the student collaborated with faculty and site mentors to develop a staff survey to guide the project direction. By week four, clinical skills advances, and the student began facilitating treatments with increasing independence; this continued for the duration of the doctoral capstone experience. At the start of week five, the survey was distributed both virtually and in a shared physical space, with results collected by the end of week six. Weeks six and seven were dedicated to analyzing survey responses and staff feedback, which drove the direction of development of educational materials in weeks eight and nine. Week ten was spent finalizing education materials, collaborating with staff on best placement, and developing a post-survey to evaluate the effectiveness of the capstone project. The post-survey was distributed at the start of week eleven and results were analyzed over the final two weeks. The last week was spent finalizing the capstone report and organizing resources to ensure sustainability.

Capstone Project Implementation

Advancement of Clinical Skills

The advancement of clinical skills in the NICU was a critical component of the doctoral capstone project. This process consisted of independent research, clinical observation, hands-on experience, and mentorship. The student began by conducting independent research and utilizing on-site resources and learning modules to gain a better understanding of the role of rehabilitation in the NICU. Throughout the on-site experience, the student gradually progressed through observation to increasing hands-on skill development with guided mentorship. Mentorship and feedback were integral in refining hands-on technique and development of clinical reasoning.

The student gained experience in developmental assessments, identifying infant state cues, positioning and handling techniques, assessing muscle tone, implementing sensory

regulatory strategies, and providing caregiver education. Additionally, the student received education and hands-on experience with varying diagnoses including, prematurity, respiratory failure, failure to thrive, plagiocephaly, hypothermia, shoulder dystocia, and other genetic anomalies. This experience included learning to work with medically fragile infants requiring varying levels of respiratory support, managing lines and leads, and implementing appropriate therapeutic interventions to support development. Furthermore, this phase involved collaborating with interdisciplinary team members, including nursing, physical and occupational therapy, speech therapy, and neonatal nurse practitioners.

Additionally, the student gained experience in discharge planning through education on resources including First Steps and the NICU developmental follow-up clinic. Observing the developmental follow-up clinic provided hands-on experience in continuity of care, offering valuable insight into caregiver education and developmental delays associated with extended NICU stays. Comprehensively, these total experiences not only enhanced clinical competency for the student but also informed the development of educational materials and project implementation aimed at supporting both caregivers and NICU staff.

Creation of Educational Materials

As part of the doctoral capstone project, educational materials were developed to support caregivers and encourage family-centered care by providing accessible resources on key neonatal topics relevant to an infant's time in the NICU. This process began with a pre-survey (see Appendix B) completed by NICU staff which guided the determination of topics for educational materials. The analyzed survey results and clinical observation identified gaps and priority topics for caregiver education, which included touch in the NICU, skin-to-skin contact, developmental

positioning, sensory regulation, including environmental modifications and infant sensory systems. The capstone student created educational resources for each (see Appendix C).

The resources focused on enhancing caregiver's understanding of neonatal practices and encourage active participation throughout their NICU stay. They provided guidance on engaging with infants using developmentally appropriate methods and included education on the benefits of these approaches. Each resource contained evidence-based research and best practices in neonatal care. The resources utilized family-friendly language to support caregiver participation with resources and understanding of material. To continue maximizing usability, handouts were created with a focus on design elements to ensure user approachability and readability. Through collaboration with NICU staff, it was determined that placing the resources in the family rooms would have the greatest impact. This placement allows caregivers to access the educational materials at their convenience, promoting better reinforcement of learning and engagement.

Capstone Project Evaluation

The evaluation phase of this capstone included a mixed-methods data collection approach. A post-survey was used to collect both quantitative and qualitative data to assess the perceived effectiveness of the developed educational materials. The post-survey was designed to align with the pre-survey data to address the gaps in educational materials identified by NICU staff. While the pre-survey demonstrated strong staff competence in the provided topics, qualitative feedback helped identify a need for caregiver educational materials.

Data Collection

The post-survey was available in two formats to maximize response rates. It was placed in the NICU staff break room alongside the educational materials and was also distributed electronically via email. The survey included seven questions on a five-point Likert scale

assessing the effectiveness of the educational materials, the health literacy, and the perceived benefits to caregivers. A Likert scale was chosen for the quantitative data to allow for measurement of degree of agreement, as well as to encourage participation by utilizing a simple and quick format. Additionally, there was one open ended question to obtain qualitative feedback from staff on the content and presentation of the developed educational materials. Utilizing a mixed data methods data collection allowed for a more comprehensive understanding of the effectiveness of the capstone project.

Project Evaluation Results

The post-survey was completed by NICU staff, including the unit's occupational and physical therapists, as well as ten of the unit nurses. Both the occupational and physical therapist served as expert content reviewers, providing insight based on their extensive experience and knowledge in therapy for medically fragile and preterm infants. They evaluated the content for topic relevance and accuracy. NICU nurses, with their deep understanding and experience of the NICU environment, infant stress cues, and with providing caregiver offered critical feedback to ensure the materials were clear, practical, and applicable to their patient population and overall site needs.

The post-survey results demonstrated that the capstone project had a significant impact and benefit to the site. The results showed that between 90% and 100% of respondents strongly agreed that the developed educational materials provide adequate information on their target topics and educational needs. Additionally, 100% strongly agreed that the resources were beneficial in helping caregivers understand and support their infant's needs in the NICU, and 100% strongly agreed that the materials were written in a family-friendly language. The qualitative feedback provided further insights, including preferred locations for the resources and

overall positive comments on the educational content, language, and visual appeal. Overall, the capstone project enhanced the site by expanding caregiver resources and promoting family-centered care to encourage caregiver participation. The survey results can be found in Table 1.

Table 1

Post-Survey Results

	Strongly disagree	Somewhat disagree	Neutral	Somewhat agree	Strongly agree
Q1: These resources provide families with adequate education on the importance of reducing overstimulation for premature infants.	0%	0%	0%	9.1%	90.0%
Q2: These resources provide families with adequate education on developmental positioning.	0%	0%	0%	9.1%	90.9%
Q3: These resources provide families with adequate information on skin-to-skin care in the NICU, including benefits and optimal positioning for skin-to-skin care.	0%	0%	0%	10%	90%
Q4: These resources provide families with adequate information on appropriate sensory needs of premature infants.	0%	0%	0%	0%	100%
Q5: These resources provide families with adequate information on	0%	0%	0%	0%	100%

calming techniques
caregivers can use with
their premature infants.

Q6: These resources are beneficial to caregivers in understanding and supporting their infant’s needs in the NICU.

	0%	0%	0%	0%	100%
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Q7: These resources are written in family-friendly language.

	0%	0%	0%	0%	100%
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Q8: What feedback do you have regarding the content or presentation of these resources?

“You created a great tool for families to understand. I would love to see this packet hanging in every patient room, maybe by the couches! It is simple and easy to read with good information, but not overwhelming. Great job!”

“These materials look great and are in family friendly language that is easy to understand. There is a good balance of educational information without being overwhelming.”

“Very good, well written. Clear explanations, good visuals.”

“Maybe a little less wording on the touch in the NICU handout. It could be a little overwhelming to pts with lower reading levels. Otherwise, they all look great and useful!”

This is such great information for families (and for staff). I appreciate you including the TV, as that is something that is usually an issue with parents who are staying. Also, the visual for positioning during skin-to-skin is very helpful.”

“Great job with these resources! They would be great to have in every patient room.”

“Good job keeping the language simple enough for families to understand.”

Discussion

Overall, the capstone experience and project had a positive impact on both the student and the site. The experience highlighted family education as an area in need of improved strategies and materials. Site staff identified several limitations to effective family education, including a lack of resources and the overwhelming nature of the NICU environment. Through research, family centered care was identified to be the best practice within the NICU setting. Integrating this approach fosters caregiver empowerment, resulting in increased parental self-efficacy upon discharge and improved infant developmental outcomes for infants (Franck et al. 2020). These findings informed the capstone project's need and purpose to be enhancing family education to increase family participation, confidence, and comfortability during their NICU stay.

The pre-survey completed by NICU site staff guided the selection of topics for caregiver educational resources. Research was conducted on relevant topics to determine best practices in current literature. Research discussed the impact of a positive healing environment, including the environmental sensory implications and the impact of positioning on infant development. The physical environment consists of overwhelming sensory stimuli including bright lights and heightened noise levels (Weber & Harrison, 2019). Increased stress in infants disrupts the development of the brain by impacting structural connectivity. Developmental positioning can be utilized as intervention to reduce infant stress as it is optimal for physiological function, stability, calmness, and brain development (Altimier & Phillips, 2016). Family members can be educated to support the infant's stress signs to reduce infant stress and encourage a positive healing environment (Howe et. al., 2022).

All established project goals and objectives were successfully met during the capstone experience. These goals included developing advanced clinical skills in a specialized environment, enhancing family involvement in infant care, and creating educational resources informed by current literature. One limitation of the project was a lower response rate to the staff post survey. This was primarily due to the high volume and acuity of NICU patients at the time of distribution, which left staff with limited time to complete surveys. Additionally, while caregiver feedback could have been valuable for resource development, it was determined that surveying caregivers in such a sensitive and intense environment would not be appropriate.

Impact

The project evaluation results demonstrated that the data collected regarding the capstone project's perceived benefit suggests a positive impact on the capstone site. Staff expressed appreciation for the educational resources developed for caregivers, recognizing their value in supporting both families and clinical practice. The resources were perceived to enhance caregiver and staff knowledge, increase caregiver confidence and participation in infant care, and promote safer and more informed engagement from caregivers in the NICU environment. By sharing evidence-based therapeutic interventions, the capstone project helped to bridge the gap between therapeutic care and family education to improve the overall well-being of infants. Lastly, the capstone experience had a positive impact on student, who gained in-depth hands-on experience in a specialized area of occupational therapy.

Sustainability

Throughout the capstone experience, sustainability of the project was a key consideration to ensure the effective use of the developed resources, guiding the determination of their presentation. To promote sustainability and long-term use, the developed educational materials

were provided to the site in multiple formats and locations, including laminated in the patient rooms, organized print materials, and electronic files. The decision to post laminated copies in patient rooms was driven by the goal of increasing utilization of handouts, enhancing both sustainability and effectiveness. Organizing the new resources alongside existing educational materials allows therapists and medical staff to easily access and distribute them to caregivers. Lastly, providing electronic files ensures materials can be updated in alignment with evolving medical guidelines and research, supporting long-term sustainability.

Conclusion

Current literature indicates that hospitalization in a neonatal intensive care unit (NICU) contributes to heightened levels of stress for both infants and their family systems. Family centered care has been established as a best practice guideline within NICU environments, providing benefits such as promoting infant development and improving caregiver self-efficacy. However, implementing family centered care principles into clinical practice can be challenging. Recognizing the significant stress experienced by infants and families in the NICU environment, the capstone project focused on implementing family centered care practices through the development of evidence-based educational resources. These resources were designed to increase caregiver understanding of common NICU topics and to foster a more positive healing environment for infants. Project evaluation demonstrated a positive impact on the NICU environment. Results included staff perceptions of benefit to caregiver education and improved caregiver support to infants.

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Appendix A

Initial Interview Questions

1. Are there any specific gaps that you have witnessed or experienced with your facility that you would like to be addressed?
2. What kind of clinical skills have prior capstone students been able to gain? What might this look like?
3. What are typical conditions and diagnosis of patients seen at your facility?
4. How do your therapists utilize family centered care?
 - a. How engaged are your patient's parents with their care and treatment?
5. Are there specific resources that you all utilize heavily? Resources that you are lacking or wanting?
6. What are the specific roles of the professions in your facility, specifically with occupational therapy, physical therapy, and speech therapy? How do these roles interact?

Appendix B

Pre-Survey Questions and Results

Hello NICU staff!

My name is Mariah Pisockyj, and I am an Occupational Therapy Doctoral Capstone student. I will be on site here in the NICU over the next 3 months observing and working on my capstone project. As part of my project, I am conducting a pre- and post-survey to identify knowledge and gaps in education for staff and/or parents in the NICU. I will be looking at the relationship between positioning of infants and sensory regulation, as well as family education and participation.

The survey is to gather more information on staff knowledge, confidence, and where you all think additional resources would be helpful.

If you choose to participate, the survey will take ~5-10 minutes to complete and your responses will be kept confidential. Please note, no personal or identifiable information will be obtained.

If you have any questions or concerns, please do not hesitate to reach out. Thank you for your time and participation!

Please return to the survey to the manilla folder in the staff lounge by Thursday, February 20th.

Pre-Survey Questions:

1. Discipline

a.

Scale 1-5 (1 Not Knowledgeable at all, 5 Very Knowledgeable)

I feel knowledgeable about ...

1. The importance of positioning for premature infants in the NICU

2. How positioning affects the sensory development of premature infants

3. The short-term outcomes of proper positioning that affect long-term sensory and motor development



A horizontal scale consisting of five blue circles, each with a number below it: 1, 2, 3, 4, 5.

4. The best practice measures for developmental care in the NICU



A horizontal scale consisting of five blue circles, each with a number below it: 1, 2, 3, 4, 5.

5. The importance of incorporating family into care when available



A horizontal scale consisting of five blue circles, each with a number below it: 1, 2, 3, 4, 5.

6. Different opportunities to incorporate parents into care



A horizontal scale consisting of five blue circles, each with a number below it: 1, 2, 3, 4, 5.

Scale 1-5 (1 Not confident at all, 5 Very confident)

I feel confident to ...

1. Assess the sensory needs of an infant



A horizontal scale consisting of five blue circles, each with a number below it: 1, 2, 3, 4, 5.

2. Implement appropriate positioning techniques to support current sensory development and need



A horizontal scale consisting of five blue circles, each with a number below it: 1, 2, 3, 4, 5.

3. Educate families on sensory strategies for optimal development



- 4. Incorporate parents and caregivers into care utilizing positioning techniques and instruction when applicable to the family



- 5. Educate and encourage families to participate in care when applicable



- 6. Implement the seven core measures of the neonatal integrative developmental care model: (1) healing environment, (2) partnering with families, (3) positioning and handling, (4) safeguarding sleep, (5) minimizing stress and pain, (6) protecting skin, (7) optimizing nutrition



What areas do you think would be helpful to have additional education resources on for staff?

For families?

	Not knowledge able at all	Slightly knowledge able	Somewhat knowledgeable	Moderately knowledgeable	Very knowledgeable
Q1: The importance of positioning for premature infants in the NICU	0%	0%	6.7%	53.3%	40%
Q2: How positioning affects the sensory development of premature infants	0%	6.7%	40%	26.7%	26.7%
Q3: The short-term outcomes of proper positioning that affect long-term sensory and motor development	0%	0%	60%	40%	0%
Q4: The best practice measures for developmental care in the NICU	0%	0%	33.3%	53.5%	13.3%
Q5: The importance of incorporating family into care when available	0%	0%	0%	46.7%	53.3%
Q6: Different opportunities to incorporate parents into care	0%	0%	6.7%	53.3%	40%

	Not confident at all	Slightly confident	Somewhat confident	Moderately confident	Very confident
Q6: Assess the sensory needs of an infant	0%	6.7%	40%	46.7%	6.7%
Q7: Implement appropriate positioning techniques to support current sensory development and need	0%	0%	6.7%	73.3 %	20%
Q8: Educate families on sensory strategies for optimal development	0%	0%	40%	53.3%	6.7%
Q9: Incorporate parents and caregivers into care utilizing positioning techniques and instruction when applicable to family	0%	0%	33.3%	53.5%	13.3%
Q10: Educate and encourage families to participate in care when applicable	0%	0%	0%	53.3%	46.7%
Q11: Implement the seven core measures of neonatal integrative developmental care model	0%	0%	13.3%	73.3%	13.3%

Q9: What areas do you think would be helpful to have additional educational resources on for staff?

“Healing environments, minimizing stress and pain”

“Developmental positioning (hands near chin – not swaddled down)”

“Ways to include family for micro preemies/critical kids when changing a diaper might be too much but parents still want to help”

“Proper use of different developmental aids”

“Outcomes for positioning, education to families, incorporating families”

“Partnering with families”

“Optimal positioning for skin to skin with parents”

“Best practices for positioning by gestational age”

“How touching or tubing premature infants can affect their development”

Q10: What areas do you think would be helpful to have additional educational resources on for families?

“Infant massage”

“Why a calm/quiet environment is important for littles/sick kids”

“Skin to skin care”

“What is appropriate at what gestational age, importance of keeping noise down, cluster care, etc.”

“Importance of developmental positioning and minimizing overstimulation”

“Positioning, how positioning affects sensory development”

“Proper positioning for mirco-preemies (i.e midline positioning), Reviewing sensory needs with families (calming techniques, appropriate volume, etc.)”

“Safeguarding sleep”

“Optimal positioning for skin to skin”

“The importance of these practices/not stroking your baby, etc.”

Appendix C

Educational Materials



Touch plays a crucial role in infant development, even in the NICU. Premature and medically fragile infants have unique sensory needs and a higher sensitivity to touch; however, **gentle and intentional touch can provide calming input, stability, and promote growth.** Here are examples of supportive touch that you can provide to your baby.

SWADDLE

Swaddling an infant **provides calming input** through containment, helping them feel calm and comfortable by keeping their arms and legs tucked in. In the womb, babies are used to kicking and pushing off of you all day. Kicking and pushing against a swaddle can **help babies to regulate their movements and supports muscle development.**

HAND HUGS

Hand hugs involve placing your hand over your baby's stomach or back, holding their arms and legs in. This **makes them feel safe**, mimicking the environment of the womb. Hand hugs **can regulate heart rate, oxygen levels, and support development.** Provide even, gentle pressure - remembering premature babies are sensitive to touch that is too light or too hard.

AVOID STROKING

Stroking is movement repeatedly over a baby's skin. **Stroking a premature infant can be overstimulating** for their immature nervous system. Rather, try providing a gentle hand hug over their chest and tummy. Still touch provides comfort without overstimulating your baby.

TOUCH IN THE NICU

SKIN TO SKIN CARE

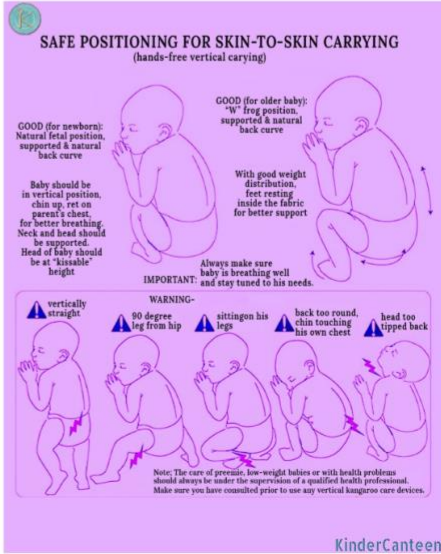
WHAT IS IT?

Skin to skin is a highly supportive form of touch in the NICU that involves placing your baby on your bare chest.

WHAT ARE THE BENEFITS?

- Regulation of heart rate
- Temperature regulation
- Regulation of breathing
- Promotes bonding
- Reduces stress levels

Optimal positioning for skin to skin involves mimicking the womb environment. While the baby is upright on your chest, **ensure their airway is clear** by turning their head to one side. Their body should be flexed, similar to fetal position, with their **arms and legs tucked in.**



POSITIONING IN THE NICU



WHAT IS DEVELOPMENTAL POSITIONING?

Developmental positioning is the act of positioning infants in ways to **support a baby's physical and neurological development**. In the NICU, it often involves mimicking the position babies hold in the womb.

THE IMPORTANCE OF FLEXION

Flexion is placing a baby in a curled position. In the womb, babies are developing and resting curled up in a ball (flexion). Once in the world, infants rest in extension - arms out and down, back flat, legs out and flat.
Maintaining a flexed, tucked position supports muscle tone, development, and self regulation.

THE IMPORTANCE OF MIDLINE

Optimal positioning for infants is head and body in midline - where the baby's head, hands, and feet are centered.
Keeping the baby's head and body aligned encourages symmetrical development. Symmetrical development is important for movement milestones that develop later on, such as rolling over and crawling.

POSITIONAL AIDS

In the NICU, we use positional aids to help support your baby's comfort, posture, and development. These aids help with head shape and promote developmentally appropriate positions. However, **we do not recommend them for safe sleep at home.**

CALM ENVIRONMENT



The NICU can be overwhelming for premature babies, who are accustomed to the calm and protective environment of the womb. The womb is dark and quiet, while the NICU is often bright and filled with noise. Creating a calm environment helps support your baby's development, comfort, and overall well-being.

While many aspects of the NICU are medically necessary, here are ways to create and maintain a calm environment for your baby.

NOISE REDUCTION

- **Talk softly to your baby** - Hearing your voice helps with their development
- **Use quiet voices** when talking
- **Keep the tv volume low or off** - Too much noise can be overwhelming
- **Close the door** - This helps reduce outside noise

LIGHTING AND SIGHT

- **Use dim lighting** when possible - Gradually transition to brighter lights to avoid startling your baby
- **Follow natural light cycles** - Keep the room brighter during the day and darker at night
- **Encourage eye contact when your baby is awake** - Looking at your face helps with their visual development



HEAD PREFERENCES

WHAT IS A HEAD PREFERENCE?

A head preference is when a baby **continuously** prefers to **turn their head to one side**. They occur often in babies because infants do not yet have enough strength to hold their heads in the center of their bodies.



WHY IS IT IMPORTANT?

- If a baby always looks to one side, it can cause the head to be flatter on one side - we want to **help their head shape develop equally**
- Neck muscles may get tight on one side - the tighter the muscles get, **the harder it is for the baby to turn their head** the other way
- It's important for babies to look both directions - this helps them use both sides of their body to **support strong and balanced muscle development**

WHAT TO DO

- **Encourage head turning to both sides** - gently guide your baby's head to the less preferred side
- **Switch up positioning** - alternate your baby's head position when you put them back in their crib
- **Hold your baby in different positions** - hold them in positions where they have to turn their head to look at you
- **Ask your care team** - PT, OT, and nursing are great resources for questions

RESOURCES

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