

The Nurse's Role in the care of neonates diagnosed with
Neonatal Respiratory Distress Syndrome using
an Individualized Family-Centered Care Approach

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Abstract

This thesis describes a pilot qualitative research study used to explore the role of Neonatal Intensive Care Unit (NICU) nurses in caring for neonates with Neonatal Respiratory Distress Syndrome (NRDS) using an Individualized Family-Centered Care (IFCC) approach. My objective was to identify specific nursing interventions and considerations taken for an IFCC approach to promote positive outcomes for patients with NRDS. For this project, I interviewed NICU nurses with experience working in a level III or IV NICU to understand what it takes to cultivate an IFCC nursing approach and how NICU nurses use IFCC to enhance positive outcomes for the patient, family, and nurse. Data was analyzed using a qualitative content analysis method and manual coding to identify themes. The findings indicated that the interventions discussed fell into one of two categories: Developmentally Supportive Care (DSC) and Family-Centered Care (FCC). While there is currently a greater emphasis on practicing DSC, this study revealed the use of FCC and how FCC plays an equally important role. When used in conjunction, neonatal nurses can tailor their care to meet each individual family and patient's needs. This collaborative approach between the two care concepts can be referred to as IFCC, and results in positive patient outcomes and a more positive family experience while in the NICU.

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CHAPTER I

Introduction

The purpose of this research study was to answer the question: “What interventions do neonatal nurses take to promote Individualized Family-Centered for their patients diagnosed with Neonatal Respiratory Distress Syndrome?” There is a lack of research looking at the implications of family-centered care (FCC) in neonates with Neonatal Respiratory Distress Syndrome (NRDS), and there is a clear need for further exploration of its influence on producing positive patient outcomes. It is hypothesized that there are specific nursing interventions taken using an Individualized Family-Centered Care (IFCC) approach that promote positive patient outcomes. This study sought to identify these interventions and further define what it takes to individualize FCC.

Registered Nurses (RNs) working in the Neonatal Intensive Care Unit (NICU) have undergone extensive training to prepare for the responsibility of providing critically important care to very sick newborns. These healthcare heroes take on the immense emotional and physical requirements needed to be a nurse in this field by not only providing nursing care, but also providing comfort and guidance to their worried families. Their dedication to patient advocacy, safety, and family-centered care is unmatched, specifically when it involves their role in administering care to patients with one of the most common and serious conditions seen in the NICU—Neonatal Respiratory Distress Syndrome.

NRDS is a debilitating condition in which premature infants struggle to fight for every breath they take due to immature lungs. It is most common in infants born earlier

than 32 weeks, because their lungs are not yet fully developed due to the lack of surfactant – a necessary substance that works to keep the air sacs in the lungs inflated (Niemarkt et al., 2017). This condition increases in occurrence and severity for the severely premature and very low birth weight neonates. Yadav et al. (2021) elaborate on the prevalence of NRDS as “98% of babies born at 24 weeks had Respiratory Distress Syndrome, while at 34 weeks, the incidence was 5%, and at 37 weeks was less than 1%”. Dyer (2019) goes on to describe the condition as being the number one cause of death in premature infants, and even the survivors may still find themselves at risk for a lower quality of life as they are at an increased risk for developing chronic lung disease and neurodevelopmental delays.

To provide the necessary care for these patients, one aspect of nursing practice known as FCC has becoming increasingly popular within several NICU settings. Through the individualization of this approach, nurses are playing a vital role by promoting and encouraging family participation as active members of the healthcare team. This is done by considering each family’s cultural, social, and spiritual needs and adjusting the plan of care as needed. As a result, NICU nurses are finding that patients and their families are having more positive outcomes and experiences. There is a lack of research identifying the steps taken to individualize care under these conditions, and a need to solidify this complex approach as evidence-based practice. This study intends to take this concept a step further by exploring the interventions NICU nurses perform to define IFCC as it relates to the care provided for neonates with NRDS.

CHAPTER II

Thesis Statement

The goal of this study was to explore care performed by NICU nurses and the outcomes of their patients diagnosed with NRDS when IFCC has been used in the assessment and treatment of neonates diagnosed with NRDS. Considering the lack of research studying IFCC with neonates who have NRDS, there is a clear need for further exploration. This study analyzed NICU nurses' responses to an interview, which consisted of key questions that reflected their perceptions of IFCC, and their identification of physical and emotional interventions provided to neonatal patients and their families. The information that this study may yield could be beneficial to current and future NICU nurses seeking positive outcomes for their patients diagnosed with this condition.

CHAPTER III

Literature Review

An overview of current research on NICU care concepts, the role of a neonatal nurse, and details of what encompasses NRDS are pieces of vital background information that are necessary to understand the components of this study, and to recognize the implications of its results. This literature review details an overview on how DSC evolved, current considerations for FCC, defining characteristics for NRDS, and nursing management of NRDS. Two of these topics are further elaborated and may be referenced as supplemental information: Defining NRDS (See Appendix B) and Clinical Management of NRDS (See Appendix C).

Developmentally Supportive Care

The idea of DSC within the NICU has been present since the first NICU was established in 1960 at Yale New Haven Hospital. Since then, this concept has become a crucial component in maintaining positive outcomes for these patients. It is the foundation for all evidence-based practice and clinical guidelines for treating sick neonates, and a vital component for integrating IFCC.

Florence Nightingale famously pioneered the concept that nurses are responsible for cultivating an environment that promotes healing (Nightingale, 1859). The foundation for care in the NICU starts with a developmentally supportive environment that provides safety for the premature neonate to heal and grow in. This may include hands-on skills and nursing interventions such as administering medications, feeding and bathing, or monitoring hemodynamic stability. It may also include outside measures such as providing a therapeutic environment through reduction of sensory stimuli and promoting

sleep. Recent literature appears to focus on the significance of DSC in the neonate's physical recovery, as well as its impact on the maternal infant bond. Through this it can be gathered that DSC is considered an integral part of evidence-based practice in the NICU and is expected to be a reoccurring theme throughout this study (Griffiths et. al., 2019).

Family-Centered Care

FCC is a concept that is becoming more prominent in neonatal health care as we recognize the impact of active family involvement in improving patient outcomes (Gómex-Cantarino et al., 2020). FCC is intended to educate and encourage parents' participation in their baby's care, which can lead to numerous benefits: create a foundation for positive family dynamic, encourage maternal/paternal-infant bonding, and physiological improvement for neonates. In the last 30 years, we have seen a transition in the standard of care from limiting family interaction to promoting it. Although this information is beneficial, there is a lack of research defining how neonatal nurses should individualize this concept in specific practices. This study intends to explore potential interventions and opportunities where FCC can be further encouraged and individualized in NRDS.

Defining Neonatal Respiratory Distress Syndrome

NRDS, also referred to as hyaline membrane disease, is the most common clinical syndrome seen in the NICU. It results from underdeveloped lungs failing to produce adequate surfactant, which leads to decreased lung compliance. Hypoventilation, hypoxemia, and respiratory acidosis can also progress this diagnosis. This impairs gas exchange and can severely affect oxygenation and ventilation. Common manifestations

of NRDS include physical signs of respiratory distress (tachypnea, nasal flaring, chest retractions, cyanosis, and expiratory grunting), abnormal Arterial Blood Gas levels (ABGs), and the presence of ground glass opacification, indicating atelectasis, on a chest x-ray (El-Malah etl al., 2015). Comorbidities that may also be noted are pulmonary hypertension, neonatal pneumonia, or sepsis. NRDS and its complications remain the number one cause for neonatal death and require aggressive intervention.

Clinical Management and Treatment Plan

Successful treatment of NRDS requires a collaborative approach from the healthcare team to include diligent monitoring of the patient's status, critically evaluating and adjusting the plan of care as needed, communication, and involving the family through IFCC. NICU nurses and NNPs are tasked with the responsibility of being aware of the most up-to-date clinical practice guidelines and utilizing evidence-based practice for their patients. This includes being aware of current diagnostic testing parameters, available treatment options at their facility and understanding the vital role they play in the neonate's journey to recovery.

Current diagnostic criteria vary based on facility and medical provider's discretion. Perinatal screening may occur prior to delivery when possible NRDS is suspected by collecting amniotic fluid via amniocentesis to determine fetal lung maturity (Visconti, et. Al., 2018). Neonates with this condition can decline rapidly, and it is often necessary to prioritize stabilization of the baby over confirming a definitive diagnosis if prescreening is unavailable or does not give a clear indication that RDS is expected. Neonatologists and NNPs may use the following criteria to give an official diagnosis of NRDS: extensive atelectasis present on chest x-ray, ABGs that reflect respiratory and

metabolic acidosis and hypoxia, and the presence of previously mentioned physical manifestations.

One highly effective treatment for NRDS that is commonly seen is surfactant therapy. Surfactant is a substance found within the alveoli of the lung that helps to facilitate appropriate gas exchange. Premature infants are often born with a surfactant deficiency due to their underdeveloped lungs. This form of treatment involves the administration of synthetic surfactant that will reduce surface tension in the alveoli and increase lung compliance, which can improve the neonate's respiratory status and lower mortality (Polin, Carlo, 2014). Additional measures, such as invasive and noninvasive respiratory support, will almost always be seen with these patients.

The clinical management of NRDS requires a multidisciplinary approach that involves both NICU nurses and NNPs. Neonatal nurses have successfully passed their National Council Licensure Examination for Registered Nurses (NCLEX-RN) and may be certified in Neonatal Intensive Care Nursing or Neonatal Resuscitation. They care for one to two patients during their shifts and are responsible for implementing treatments ordered by the neonatologist or NNP. This may include surgical care, administering high risk medications, resuscitation, phototherapy, managing patients on a mechanical ventilator, and providing chronic care management.

NNPs are an integral part of the healthcare team involved with the neonates diagnosed with NRDS. They are advanced practice nurses (APN) who have obtained their Master of Science in Nursing (MSN) degree, passed their Nurse Practitioner board exam, and trained specifically in neonatal care. They oversee a larger caseload of patients and consult and collaborate with patients' families and neonatologists. Their role includes

ordering medications and labs, diagnosing conditions, performing some invasive procedures, and evaluating and changing medical treatments as the patient's case unfolds. Both NICU nurses and NNPs are key players in the care of a patient with NRDS and have a direct impact on the parents and families of these patients.

CHAPTER IV

Methodology

This study was approved by MTSU Institutional Review Board (IRB) on December 10th, 2021 (See Appendix D). Convenience sampling was used based on word of mouth and availability of NICU nurses with experience practicing in a level III or IV NICU. Participation was voluntary and participants were not compensated. The sample size was 5 and included two NNPs and three RN, BSN NICU nurses. Prior to each interview, informed consent was obtained, and participants were provided with IRB information related to the study. Data was collected through a virtual interview on Zoom where participants were asked to reflect on their career by answering a series of ten open-ended questions related to individualizing FCC and the care of neonates with NRDS (See Appendix F). The interviews lasted, on average, 30 minutes and were audio recorded. Once data saturation was reached, a qualitative content analysis method was used to study and identify prominent themes in interview responses. Following transcription, audio recordings were deleted, and a method of manual open coding was used. Initial reading was completed by the student researcher, with second and third readings completed by Dr. Amanda Flagg and Dr. Sherri Stevens, respectively. Comparison of data within interviews resulted in grouping codes that later revealed common themes. Credibility was achieved by maintaining confidentiality of participants and providing highly detailed transcriptions for readers to make adequate judgments.

CHAPTER V

Results

As indicated in my methodology, data saturation was reached after five volunteers participated in individual virtual interviews. The results and following discussion are based on the data analyzed from the responses of those five participants.

Initial readings of the interview responses showed similar ideas and practices. Nursing care for NRDS did not vary greatly, and interventions were supported by evidence-based practice. An additional review indicated several corresponding topics, and a deeper analysis revealed that all nursing interventions for neonates with NRDS can fall under two main themes: DSC and FCC. Contributing factors, considerations, and interventions were categorized into four subthemes for each that were further explored. The figure below demonstrates the relationship between the two themes as it relates to the practice of IFCC.

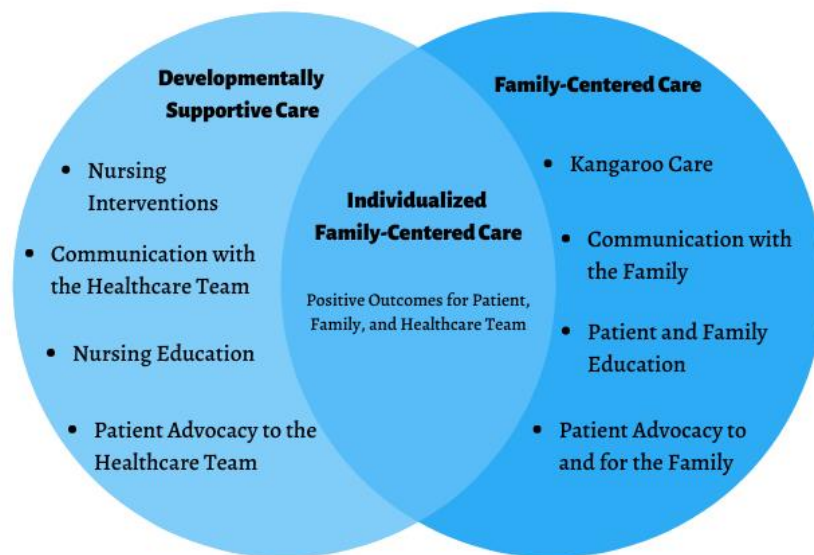


Figure 1: IFCC Care Model

DSC was the first main theme identified. Within this, it was found that nursing interventions, communication, nursing education, and patient advocacy were key measures incorporated into the care of NRDS. FCC was an additional theme found to be prominent in individualizing care for neonates. As with the former, four corresponding subcategories were identified to further support its significance—kangaroo care, communication, patient/family education, and patient advocacy. The following chart is intended to list and explain common nursing interventions for NRDS patients reported by participants in the study. It is not conclusive and is mainly a reflection of interventions that involve direct patient contact and care. Other nursing interventions that influence IFCC, such as communication and education, are elaborated in the Chapter VI.

NICU NURSING INTERVENTIONS

| Developmentally Supportive Interventions | Family-Centered Interventions | Individualized Interventions |
|---|---|---|
| Intubating/mechanically ventilating, monitoring ventilator alarms and any lines (IV, umbilical, etc.), drawing labs, monitoring ABGs, maintaining appropriate fluid/electrolyte balance, stabilizing blood glucose levels, monitoring vital signs and respiratory status, suctioning, assessing and maintaining thermoregulation, preventing infection, bathing, and feeding. | Using Kangaroo Care to allow parents to actively care for their baby while in the hospital as much as safely possible (feeding, bathing, soothing, etc.). This facilitates the parent-infant bond, provides a more positive and interactive experience, and encourages a healthier family dynamic post discharge. | Adjusting cluster care times based on the parent's schedule so they can be present and actively involved with feeding, bathing, and soothing the patient. |
| Administering surfactant, opioids/narcotics, sedatives, antibiotics, or other medications. | Assessing the family dynamic, encouraging them to be involved, addressing any barriers, and assessing their physical, spiritual, and emotional needs and how those needs may effect the patient. | Communicating with the family and educating them in their preferred way, ensuring that their requests are communicated with the rest of the healthcare team (breast milk instead of formula, who is allowed to visit, etc.), providing 24/7 . |
| Mimicking the in-utero environment with reduction of sensory stimuli (keeping noise levels down, dimming the lights, minimizing handling, etc.) and containment touch. Maintaining a calm and nurturing environment by using music boxes, non-nutritive sucking (pacifiers), swings, water beds, rocking, cuddling, and other comfort measures to soothe the baby. | Parents performing a "72-hour care-by-parent" prior to discharge to show that they are prepared to take their baby home and safely care for all their needs. Nurses provide additional teaching, if needed, to ensure patient will be well cared for. | Advocating for the patient's needs (not allowing the parents to hold the patient if they are not stable so they can rest, and instead offering an alternative time that they can or allowing them to sit with their baby). Advocating for the family by giving them the option to hold a meeting with their baby's care team to discuss the plan of care and address any concerns. |

Figure 2: Table of NICU Nursing Interventions

The two themes were analyzed, and there is a clear association with outcomes when these concepts are used in conjunction to form an IFCC approach. Most situations resulted in positive outcomes that appeared to make significant difference in patient and family care. Additionally, potential negative consequences were discovered and considerations to avoid those outcomes were addressed in the discussion of this research. An in-depth explanation of the study's findings and its implications will be further elaborated on in Chapter VI.

CHAPTER VI

Discussion

Nurses play a pivotal role in promoting positive outcomes for neonatal patients by tailoring their interventions to meet both the patient's and family's needs. This study sought to identify the specific nursing interventions NICU nurses do to individualize their care for patients with NRDS. NICU nurses were interviewed to gain insight related to specific nursing actions, interventions, and judgement they take when caring for their patients born at or earlier than 32 weeks' gestation and diagnosed with NRDS. Initial review of the data showed similar responses. Upon further exploration, the data revealed two overarching care concepts, each with subsequent themes, that nurses adopt into their practice: Developmentally Supportive Care and Family-Centered Care.

Developmentally Supportive Care

The first major theme identified was the concept of DSC. A deeper review revealed four corresponding components, which include: nursing interventions, communication with the healthcare team, patient advocacy, and nursing education.

DSC is the foundation for all evidence-based practice and clinical guidelines used for treating sick neonates, and is crucial for maintaining positive outcomes in these patients (Coughlin et al., 2009). The safest and most developmentally support environment a baby can be in is its mother's womb. When a neonate is born prematurely, DSC is used to promote an adequate healing environment for the premature infant to achieve appropriate growth and development. NICU nurses are tasked with maintaining an outside environment that mimics the inside of a mother's womb through several interventions. Reducing sensory stimuli, such as noise and lighting, and minimalizing

handling whenever possible, was mentioned by all participants in the study. They collectively went on to elaborate on this, stating that utilizing the time spent with the patient while keeping it at a minimal amount is vital to ensuring their care is developmentally supportive:

P1: We know that the excessive stimuli is detrimental to the baby's ability to adapt to the surroundings and stabilize themselves. We combat this with minimal handling and clustering care. Babies don't have the ability to go into a deep sleep if we do that, which we know is essential to help them recover.

Nurses use 'cluster care' by bundling their interventions to occur at specific times throughout the day to prevent repeatedly disturbing the patient. This concept is highly encouraged and is shown to be a part of evidence-based practice in the form of a clinical practice guideline. One participant was able to expand on how their facility prioritizes cluster care based on gestational age or patient status:

P4: If they are less than 32 weeks, our hospital does assessments every 6 hours, and we will only be at the bed at those times unless otherwise needed, to allow more time for baby to sleep and to be undisturbed. Sleep is important because that is when babies really grow and develop. If they are under 32 weeks, we want them to get as much sleep and as little stimulation as possible. If they are over 32 weeks, we usually get in their bed every 3-4 hours, depending on what they have going on. We do big assessments every 6 hours, and then at the 3-hour mark in between we do things like change their diapers, feed them, and do smaller assessments.

Promoting neonatal comfort is an additional consideration for ensuring their environment is developmentally supportive. This may include pharmacological pain

management or nonpharmacological methods to soothe the infant. Participants were able to detail various options for this that appear to be based on facility and other conditions the patient might be facing. Within these, there are many opportunities to promote and individualize FCC, to be further elaborated on later:

P1: Pain management in the NICU is a tiered approach. It is both pharmacological and nonpharmacological. For a baby with NRDS who is intubated, we would look at a short-term anti-anxiety medication with some intermittent or scheduled narcotic pain medication. Nonpharmacological is essential, you can't have one without the other. Skin to skin with mom as quickly and as safely as possible, nonnutritive sucking where we get permission from the parents to calm the baby with a pacifier, positioning and containment where we swaddle them tightly, and reduction of stimuli. Neonates love to be in a secure, controlled, tight environment. We use soft therapeutic music and rocking motions—we have a lot of water beds that soothe the babies by motion—swings, cuddling, and touching.

P3: There is nothing really painful about NRDS. Being intubated can be uncomfortable, but not painful. We do give our babies a lot of sedation. If they are critically ill, we will put them on a Versed drip, or we can put them on morphine or fentanyl drips, but it's not directly related to NRDS.

P4: Music boxes help babies to soothe and them and make them feel better. We can do what is called containment touch, which is when you put your hands on the baby in a little bit of a firm manner, which helps them feel like they are still in mom's womb. It contains them so they aren't flailing around everywhere and that helps calm them down too. Also, removing stimulation by making it dark and quiet. If we have a baby that

requires special attention to be quiet around, we will sometimes put signs up around their bed for people to know to be extra quiet around that baby.

P5: We score them in our charting, and we look for cues. A lot of these patients don't get treated for pain, it is more like comfort measures such as: repositioning them, dimming lights, music, and compression devices.

Besides cultivating the appropriate environment, nursing care also includes other responsibilities when caring for patients with NRDS. NNPs described their daily tasks as directing the clinical practice of a patient with NRDS. This includes adjusting the plan of care, writing orders, and performing more advanced, high-risk interventions for sick neonates. In the moments following a preterm delivery, NNPs provide the immediate resuscitation and stabilization of the newborn. This may include intubating the patient and then later overseeing the various modes of MV. One of the most important interventions for NRDS treatment is administering surfactant. NNPs are licensed to perform this task, although participants reported that it is now usually performed by Respiratory Therapists (RTs). They are also responsible for making day to day decisions, rounding on the babies, deciding nutritional needs, making notes of respiratory or fluid volume changes, and ordering blood products, antibiotics, surfactant, or other medications.

RNs work with NNPs through attentive monitoring and providing direct patient care. Developmentally supportive nursing interventions for patients with NRDS may include drawing labs, monitoring their arterial blood gasses, administering medications, maintaining the patient's fluid and electrolyte balance, stabilizing blood glucose levels, monitoring oxygen levels and other vital signs, assessing the baby's thermoregulation,

bathing the infant, and tube or bottle feeding. Due to their poor lung function and underdeveloped immune system, patients with NRDS are at increased risk for infection, specifically pneumonia, which may lead to neonatal sepsis. Patients with extreme cases of distress may require the use of invasive respiratory support, further increasing the likelihood of infection on top of their already prominent risk, and there are additional interventions to combat this.

P5: We have different bundles depending on if they are on the ventilator, at risk for pneumonia, at risk for neonatal sepsis, have a central line, etc. For intubated patients, a lot of our care is preventing pneumonia, so we keep their HOB elevated, suction the endotracheal (ET) tube every four hours, 'scrub the hub' for central lines, and changing fluids every 48 - 96 hours.

Communication with the healthcare team was also an evident subtheme that contributed to the successful care of a neonatal patient with respiratory distress. In addition to neonatologists, NNPs, and RNs, participants reported collaborating with various other healthcare professionals, such as: RTs, optometrists, occupational and physical therapists, pharmacists, and social workers. RTs, were highly mentioned, and there was a clear correlation between their communication with nurses to determine the appropriate respiratory support and surfactant for the patient's ever-changing condition.

P4: We work closely with respiratory therapists with the baby's care to make sure all their equipment works well and that their blood gases are good. Our respiratory therapists do oxygenation weaning and ventilator settings.

Additional communication with the healthcare team also occurred in the form of patient advocacy, another recurring subtheme throughout the interviews. With their

patient's best interest always at mind, the data revealed that it is not uncommon for RNs to approach NNPs and neonatologists to voice their concerns, as well as provide their personal recommendation, if warranted. There were accounts from both RNs and NNPs where this was reported. When critical thinking skills and experience are paired with attentiveness to their patient's condition, and any minor change in their baseline, NICU nurses are equipped to advocate for their patients when they are in need of additional or adjusted care:

P3: We've got a baby with a massive encephalocele, and our nurses work so hard with that baby. These are patients that are difficult to care for and they do a great job for them. They stand up for them, if they think they baby is in pain or anything like that then they will call you and ask for something. They are very focus on patient advocacy, and they get mad at us if they think we aren't listening to them. I always try to listen to our nurses and our parents because a lot of times they will be the ones that notice things. There are some nurses who cry wolf and it's almost like they want your attention, but the majority of our nurses are very focused on advocating for their patients and their parents.

P4: We have no problem grabbing other nurses and seeing what they think of the baby or asking them what they would do, especially if they have been a nurse for longer and have seen more things. Communication is a big one, also knowing your baseline vitals. Having discussions when you feel like something isn't right, but you aren't sure if you need to go to the doctor.

P5: We advocate for our patients by talking to providers and making sure everyone is on the same page. A lot of times the doctors don't get to know the infants as

well and they are not there at bedside to see how the infants are acting. Patients also have a primary nurse in their chart that is usually assigned to them, so they are getting the same patients and the patients are getting the same nurses who know them. Later down the road after 32 weeks, we consult OT and PT so that all those people are put into the care as needed.

The final subtheme identified under DSC was neonatal nursing education. When asked about training specific to their role in the NICU, participants reported that there was little exposure in nursing school to prepare them for this field. Prior to starting their careers in the NICU, the overall idea of DSC was not new, but there was a clear lack of scenario-specific training until they came to the unit for orientation. NICU RNs with less than five years' experience reported that they did not receive neonatal specific training during nursing school or prior to their orientation period after being hired. Both new and experienced RNs and NNPs agreed that there is a need for new NICU nurses to have unit specific training prior to caring for patients. This is especially important for new grad nurses with no NICU exposure, versus a seasoned nurse transferring in from another specialty who may have an easier adjustment. Critical thinking skills develop and grow stronger with more exposure and experience, and NICU nurses with a longer orientation period reported feeling more confident in their skills.

P1: The newer nurses are coming out of school younger and with less experience. I think they are very task-oriented because they have not had the exposure and ability to communicate and learn the proper way to communicate with parents. They are so focused on learning how to be a good NICU nurse and that tasks that come with that—giving meds, assessments, learning the ventilators, etc.—that the bedside communication

is not as strong. Because we are so short staffed across the nation, NICU nurses may have multiple babies that require frequent assessment and interventions, and that has become the priority.

P3: A lot of nurses coming out of school today have the head knowledge about some things, but I don't think it's as good as what it used to be. You have their basic education, but anyone who is going to work in the NICU needs to go through a program that specifically teaches NICU. Not all facilities have that. Those inexperienced NICU nurses caring for babies with NRDS are not capable of saying that they think their patient is in distress.

Participants were also asked about any education or training they received regarding the concept of FCC, to be further elaborated on later. No participant was able to recount any specific training about FCC, but one did report having regular emails encouraging kangaroo care, which is closely related. More experienced RNs were asked to comment on their observations of newer NICU nurses, and the consensus was that new grad nurses in the NICU are very task oriented. Some reported that, despite this, their newer nurses still provide excellent FCC. Others revealed that their less experienced nurses lack an awareness and understanding of the importance of individualizing care based on family dynamics and resources. When asked about the amount of training received on FCC before working in the NICU, two participants reported the following:

P4: We really learned as we went. Our preceptors go through stuff as situations come up. We really didn't get a whole lot of that once we started aside from the fact that family and support is important. We kind of just jumped in and got patients with our preceptor.

P5: Most of it came from school and once you start working, they don't necessarily call it family-centered care, but they do encourage things that fall under that category like k-care or communicating with parents. Some hospitals have classes for new grads, but I personally didn't have anything about family-centered care.

While this study did not seek to analyze the effectiveness of current NICU nursing education, there appears to be a need for further exploration of nursing education and training for FCC if it is to become an integral part of these patients' care. Based on participant responses, it can be inferred that there is more education related to DSC than FCC. Current training standards for FCC appear to vary based on facility and unit resources, whereas DSC is evidence-based and considered a necessity for excellent care of the ill neonate.

Family-Centered Care

The second theme identified, equally as prominent as the first, was FCC. As with the former, an in-depth analysis showed four correlating subthemes: kangaroo care, communication with the family, patient advocacy, and patient/family education.

Neonatal nurses employ interventions outside their daily care tasks to promote FCC. Data showed that 'kangaroo care', also termed 'k-care' and 'two-person care', is a prominent tactic used. Kangaroo care is an important factor in FCC through facilitating the paternal and maternal-infant bond, helping the parents grow more confident in their ability to care for their baby, and ensuring that parents are playing an active role in the plan of care. Most notably, it is essential for the baby, as kangaroo care has been reported to make a drastic difference in patients' response to treatment and is associated with more positive outcomes.

P4: Our parents are allowed to do the containment touch, they can change diapers, check temperature, and they can also do what is called kangaroo care or skin to skin. It's where mom or dad puts on a hospital gown, and we put baby directly on their skin and it helps regulate baby's temperature and respiratory rate.

P5: Kangaroo care is a big one. They encourage that, we have specific places to chart that, we get regular emails about it. For most patients, they want us to K-care no matter how sick they are.

It is considered a part of evidence-based practice and involves parents providing hands-on care as much as safely possible. While they may not directly perform high-risk interventions like medication administration and procedures, they are often invited to assist through 'containment touch', where they gently but firmly hold their baby to mimic the tight feeling in the womb and minimize movement while the nurse provides care. Interview responses did show that kangaroo care is encouraged in most facilities, but to varying degrees. Some hospitals will only allow parents to feed and bathe their baby, whereas others may allow them to participate in containment touch.

Communication with the family is arguably the deciding factor between a family who has a positive experience in the NICU and a family who has a negative experience. If the NICU team is aware of a preterm delivery ahead of time, communication will ideally begin before the mother goes into labor. When questioned about communication strategies and routines, Participant 1 reflected on their experience as an NNP to provide an in-depth explanation of the several steps they take to facilitate a collaborative and trusting relationship with the parents. NNPs and neonatal nurses must help them understand what is going to happen at the time of delivery, give them the best-case

scenario, and explain potential problems as well as how they might be addressed. It is important to prepare the parents by giving different perspectives, while also trying to maintain some of their vision with the changes that are going to happen.

P1: I think that the one thing that is essential is to go in and be able to talk to the mother or parents and include the rest of the family, if warranted, beforehand so they have some kind of plan in their head. A lot of times parents are overwhelmed by the fact that they are going to have a preterm baby that isn't going to breathe. Their vision is different than a medical person's vision. So, you go in and talk to the parents, and immediately you have to assess their personalities, their culture, their ideas, what's possible/not possible for them to do, and it really sets the stage for developing the relationship between the nurses/facility/NPs and family so they aren't going in blind. It's essential to paint that picture for the mom: both clear, positive aspects of it and then introduce what might deviate from what they might think.

Communication with the family is not just important leading up to birth; it plays an equally important role throughout the patient's recovery. It keeps the parents informed, incorporates them as active members in their baby's health, and can encourage development of the paternal/maternal-infant bond, giving them the chance to see their baby as more than a sick patient.

P1: Providing up to date information once the baby is born and immediate resuscitation is complete; the parents may have seen us intubate the baby, and at some point, you've got to tell the parents "This is the tube that is helping the baby breath, this is the IV, this is what we have done, these are the good things about this baby, this is where we are at now, etc." and then once you get to the nursery and changes are made

again, constantly update the parents and even provide pictures if that's what they want. Telling them something good or fun about their baby, so that they have a good feeling about what is happening, is important. A lot of times they are afraid because of the mechanics and environment of the NICU. Once the baby is in the nursery and mom/dad are able to come in, you want to encourage them to touch the baby. Information is your best tool in facilitating that interaction with the parents and the baby.

Introducing the family to the team that will be caring for their baby, including the neonatologist, NNP, nurses, and RT, also aids in easing the parents' nerves and keeps them involved in the plan of care. Common questions and concerns that nurses prepare to address are when the baby can go home, when mom can breastfeed, and how their baby will receive nutrition (bottle/breast versus tube fed). As a general guideline, most families can initially expect their baby to go home around the time of its original due date—though that is not always the case. Additional considerations to be aware of include making note of what the original birth plan was, if they plan to breastfeed, if formula or breastmilk is preferred, what other family members the parents want to involve, and how the parents will be supported throughout this experience. Two participating NNPs reported meeting with the family personally to assess the situation and make note of the considerations mentioned above; however, it was implied that not all APN and providers practice this. As such, NICU nurses are responsible for ensuring that the family's wishes are communicated to the rest of the healthcare team and maintaining these desires throughout their baby's stay.

Participant 1: One question moms always have is "When can I breastfeed?"

Babies with RDS who are intubated/on ventilatory cannot breastfeed, and they may ask

how their baby is going to receive nutrition. Some moms don't want their infant to receive formula. We are never going to feed a baby with RDS, it is just too dangerous. You have to explain to them how they are getting their nutrition. Even though the baby can't breastfeed now, explain to mom what we want her to do to help start her milk so that when the baby is ready to it, it's available. They may ask if the baby is going to stay in the room with them or be taken away. Always allow parents to ask questions, even if you have already answered them, because what I say may not make sense. Be prepared to answer them again and reword. You have to keep into consideration the cultural differences between families and how they react to good news/bad news, maybe with indifference, and be aware of all those things.

Patient advocacy can occur in many forms with FCC. Nurses reported needing to advocate for their patients to not be held or stimulated during sleeping hours, which is when the majority of neonatal development occurs. They continue to promote FCC by offering an alternative option—although parents should refrain from holding their baby during those times, they can sit by their bed as they sleep and be present during cluster care, or actively participate through kangaroo care. Nurses can go a step further with this and individualize their care by tailoring these times to the parent's schedule.

Participant 1: Up front we want to ask the mom what her schedule is and when she can be here to visit. Some facilities schedule cluster care ahead of time and other facilities schedule clustered care based on the mom's schedule so that we can include her. That is establish very quickly if that is the case. If something goes wrong, we may have to tell the mom that it's better to minimize hands on for the baby. A lot of them will be sad and defensive and others will say they understand that's what's best for the baby.

We try to say that we would prefer them to not physically interact with the baby at this time, but we would love for them to sit by the crib and talk to them.

Another way nurses advocate for their neonatal patients is by ensuring their families are fully equipped to care for their needs prior to discharge. One participant explained that their facility does a 72-hour ‘care by parent’, where nurses observe the parent(s) performing all care for the baby for 72 hours prior to being approved for discharge. Advocating for a patient in this situation may look like contacting the neonatologist to request an order for an additional ‘care by parent’ when the nurse feels that the parents or caregivers are not ready to take on full responsibility. FCC may be further incorporated by assessing the parents' knowledge level and preferred learning styles to develop a plan of action that educates and prepares them for their baby's needs. An additional concern to be aware of is patients who do not have an appropriate family dynamic to go home to. Social work may need to be called in and collaborated with to ensure that the baby will leave well cared for. This is a common occurrence for infants exposed to illegal substances and alcohol during pregnancy, which frequently leads to a diagnoses of NRDS, or those where the mother is unfit to take care of her baby alone.

P1: My priority for the baby, is the baby. I am very up front with the severity of what might happen, and I always make the parents understand that I am very in tune with their needs. I know they want to hold their baby and I let them know that I want them to get to. As soon as I can talk to them about the baby and what's been done, I will do that. I tell them that, but my priority is the baby.

Educating the family on the patient's condition, as well as its current and future needs following discharge, was noted to be one of the most important interventions

nurses can perform related to FCC. Patient education should begin long before discharge is in sight and builds off previously mentioned communication tactics. Participants reported making it a priority to take the time to orient parents to the various machines and lines their newborn may be attached to, as well as explain their purpose. Explaining information on a level that the parents can understand, and being prepared to re-explain the same information in a different manner, is expected of a neonatal nurse incorporating FCC. Individualizing care in such instances may look like changing education tactics based on the family's language or preferred learning style. One participant elaborated on their facility's resources to keep parents educated on their baby's condition by providing a conference room that they were allowed to request with the care team at any time. Parents, nurses, or providers could call a meeting and collaborate on a family-centered plan of care. Additionally, this same facility provided parents with a phone number that would put them in direct contact with their baby's nurse at any time of the day or night.

Outcomes

The data revealed both positive and negative outcomes associated with the use of DSC and FCC. No statistics were collected, but participants elaborated on various situations in which these themes were evident. All participants stated that individualizing FCC was an overall positive concept that improves patient outcomes. One participant described that on multiple occasions, they have witnessed the baby's oxygenation status improve drastically by being held skin-to-skin to their mother's chest:

PI: I have personally seen it happen many times where a baby who has been on the ventilator and not doing well has its mother come into the nursery for the first time. She sits down next to the baby and begins talking to it and touching it. I have watched

that baby literally improve within minutes based on that touch and sense of voice from the parent.

Another participant stated that the babies who have families present and involved with their care tend to go home sooner and have better outcomes than their counterparts, who will often become repeat patients in the Pediatric Intensive Care Unit:

P5: Some of our sickest babies are the ones that have parents who are willing to learn about their care needed during and after the hospital. It makes a huge difference. Even the sickest babies can do amazing after they leave if their families are super involved. Those families who don't come around or aren't really involved make it difficult. Some of them just don't know the complexity of what their child has, like with NRDS cases, and a lot of those patients end up as PICU patients down the round and don't do as well.

Despite these positive occurrences, there are occasional downsides to promoting this care concept. One participant explained that open-bed units sometimes struggle with maintaining a developmentally supportive environment due to increased noise from visiting families. Another example included parents who repeatedly choose to hold their baby outside of cluster care hours, despite being told otherwise, which disrupts sleep and may prevent adequate healing and development. Although having the family involved may be positive for the patient, the excessive sensory stimuli can be a negative factor and have poor outcomes for the neonate if not addressed.

Individualized Family Centered-Care

The data collected from this study can best be summarized as two supplemental care concepts that, when applied congruently, provide immense opportunity to

individualize neonatal care for NRDS based on the patient’s physical and familial needs. This relationship may be referred to as IFCC, and can be visually explained through the IFCC Care Model:

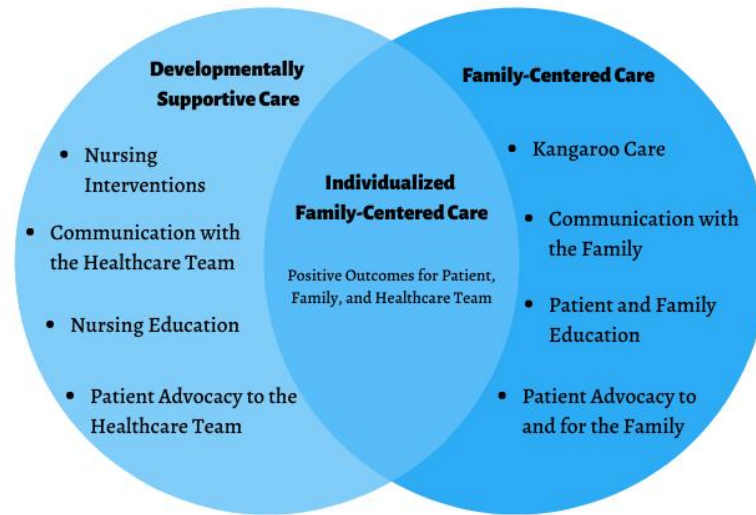


Figure 1: IFCC Care Model

Each participant was asked how they individualize their care, and what IFCC means to them:

P1: I try to establish a relationship with the parents as quickly as I can, and I don't know that that's always done. In most facilities, NPs do 12- or 24-hour shifts. I've even worked some that are 48 or 72. The parents need to see the same face as quickly as they can so they have a go to person, and the same with the nurses. We try to keep the same day and night shift nurses with the same baby so they can establish a relationship with the parents too. I always have a scenario in my mind of how I approach the patients: I never use the term "the baby" or "it". I always ask the parents if we know what the sex of the baby is, and if we say yes then I always ask what the baby's name is. I think it's very important to establish the baby's identity before it's born.

P2: It's individualized, that's the key word. Every family and patient is different. There are some things that are common based on gestational age and development, but they may manifest differently. Use the babies name and identify what is different about this baby and their circumstances – could be physical, emotional, family-related, etc. every family wants to know their baby is special and wants you to know that too, so how can you show them? Parents need to know that it's their baby, not the unit's baby.

P3: At my facility, they are extremely focused on family-centered care. Nurses are taught about it. One thing that bothers me that I see is the nurses are afraid to let the parents hold the babies when they are intubated. We have to really encourage those nurses to let the parents do that and involve RT if needed to make sure they stay stable. It's not uncommon for us to be talking to parents at 2 or 3am. Right now, I have a 12-year-old that has a baby. We work not only with her, but also work with her extended family.

P4: Every family is different and has different needs, but something our NICU does is we have cameras that you can put on the babies when we aren't by the bed so the families can watch them. They don't see anything invasive or procedures like IV insertion or PICC line insertion. Parents set up their account and are given a password that they can give to whoever.

P5: We try to get the parents to play an active role. We try keeping them well informed and encouraging them. A lot of parents are nervous because the babies are tiny, so we try to encourage them to do as much as possible to give them the confidence and promoting things like K-care. Also things like giving the parents permission to go home and rest, telling them about resources we have, making them feel involved and important

(even if its just pumping and giving colostrum). Social services do a lot and we usually consult them and they do a lot of work, such as Ronald McDonald house, meal tickets for those parents who need it, and then lots of involvement at discharge. I would define IFCC as encouraging a family to play an active role in care and trying to involve them as much as possible.

IFCC is not limited to the examples discussed thus far and is incorporated on a case-by-case scenario. The following chart summarizes many of the nursing interventions discussed in this chapter and explains some additional scenarios in which IFCC may be used. It is not a collective indication of all nursing interventions for NRDS patients and focuses on those that involve direct patient contact and care. Other interventions that are important to IFCC, such as communication and education, are previously discussed and not included in this example.

NICU NURSING INTERVENTIONS

| Developmentally Supportive Interventions | Family-Centered Interventions | Individualized Interventions |
|---|---|---|
| Intubating/mechanically ventilating, monitoring ventilator alarms and any lines (IV, umbilical, etc.), drawing labs, monitoring ABGs, maintaining appropriate fluid/electrolyte balance, stabilizing blood glucose levels, monitoring vital signs and respiratory status, suctioning, assessing and maintaining thermoregulation, preventing infection, bathing, and feeding. | Using Kangaroo Care to allow parents to actively care for their baby while in the hospital as much as safely possible (feeding, bathing, soothing, etc.). This facilitates the parent-infant bond, provides a more positive and interactive experience, and encourages a healthier family dynamic post discharge. | Adjusting cluster care times based on the parent's schedule so they can be present and actively involved with feeding, bathing, and soothing the patient. |
| Administering surfactant, opioids/narcotics, sedatives, antibiotics, or other medications. | Assessing the family dynamic, encouraging them to be involved, addressing any barriers, and assessing their physical, spiritual, and emotional needs and how those needs may effect the patient. | Communicating with the family and educating them in their preferred way, ensuring that their requests are communicated with the rest of the healthcare team (breast milk instead of formula, who is allowed to visit, etc.), providing 24/7 . |
| Mimicking the in-utero environment with reduction of sensory stimuli (keeping noise levels down, dimming the lights, minimizing handling, etc.) and containment touch. Maintaining a calm and nurturing environment by using music boxes, non-nutritive sucking (pacifiers), swings, water beds, rocking, cuddling, and other comfort measures to soothe the baby. | Parents performing a "72-hour care-by-parent" prior to discharge to show that they are prepared to take their baby home and safely care for all their needs. Nurses provide additional teaching, if needed, to ensure patient will be well cared for. | Advocating for the patient's needs (not allowing the parents to hold the patient if they are not stable so they can rest, and instead offering an alternative time that they can or allowing them to sit with their baby). Advocating for the family by giving them the option to hold a meeting with their baby's care team to discuss the plan of care and address any concerns. |

Figure 2: Table of NICU Nursing Interventions

This study was intended to focus specifically on individualizing nursing care for NRDS, but it is clear there are interventions for all patients in the NICU that strive to promote DSC, regardless of their condition. Similarly, there are interventions that specifically target family involvement. The results of this study have shown that, despite the positive implications, there is a lack of specific guidelines to outline IFCC for NRDS, as well as for many other illnesses. Due to this, it is the researcher's belief that we are missing one half of the equation to providing optimal care for neonatal patients facing critical conditions. All care provided in the NICU is intended to be developmentally supportive, and there are clear guidelines and protocols in place to ensure this, varying based on facility. There is a lack of this for FCC, and it appears that there is a lack of

emphasis on individualizing this as well. It is recommended that, in the future, we work towards promoting better outcomes by combining both DSC and FCC to create evidence-based guidelines that encourage IFCC for all neonatal patients with NRDS.

The impact of family on neonatal outcomes in the acute care setting directly relates to their future outside inpatient care and should not be taken lightly. Establishing a healthy family dynamic looks very different for parents of healthy, full-term infant than those of an ill, premature neonate with NRDS. The baby's physical needs must be considered for DSC, while the family's cultural, spiritual, emotional, and social needs must be also taken into consideration to promote FCC and facilitate the paternal/maternal-infant bond. This can have direct benefits for the patient's recovery. Nurses are responsible for encouraging these relationships and encouraging active involvement during a time that is both emotionally and physically draining for the family. NICU nurses willing to go the extra mile in their practice may do their due diligence by advocating for the patient and their family using IFCC to promote the most positive outcomes for neonates with NRDS.

CHAPTER VII

Limitations

Limitations of this study may include time, post-covid staffing limitations, a variety of demographic factors, the participant pool having experience in different geographical locations, and availability of nurses who fit the participant criteria. The major limitation was access to NICU nurses with experience working in level III and IV facilities. Although data saturation was reached, the sample size is not reflective of every NICU nurse or patient with NRDS, and these results may not be generalized.

CHAPTER VIII

Future Recommendations

While the results of this study did provide perspective on the NICU nurse's role in IFCC, it is recommended that this study be expanded further with a larger participant pool. It may also be beneficial to include an additional participant population, families of NICU patients, to better understand their perceptions of the care their baby receives. Future studies may go on to set definitive guidelines for IFCC in NRDS and other diagnoses as evidence-based practice to be utilized in all facilities with a NICU.

In addition to current orientation practices, it is recommended that NICUs have a specific training program in place during unit orientation for nurses that focuses specifically on IFCC. Finally, it could be of great benefit for facilities to utilize a report model described by Participant 1:

P1: The approach included the NNPs, nurses, and neonatologists. Nurses would give report to the neonatologists instead of the NPs. Generally, NNPs walk bed to bed with the neonatologist, giving them report from the report the nurses gave us and from our own data. In this case, they wanted the nurses to give report on the patients. They wanted the nurses to not only learn the data, but also the systems and every aspect of care of the babies so they can interact with us, you, and the parent. These reports were a very relaxed environment and over time I saw the nurses gain that knowledge and ability to communicate which is great.

This idea facilitates a stronger, more collaborative bond between members of the NICU care team and encourages neonatal nurses to be more adept at understanding and

communicating their patient's needs. As a result, it can open the door for additional opportunities to incorporate IFCC into the plan of care.

CHAPTER IX

Conclusions

The results of this pilot study answered the question originally posed, “What interventions do NICU nurses take to promote Individualized Family-Centered Care for their patients diagnosed with Neonatal Respiratory Distress Syndrome?” My intention in conducting this research was to identify interventions for individualizing FCC that may be used to create future definitive guidelines for incorporating IFCC in the NICU. Participants with high-level experience caring for NRDS patients in level III and IV facilities contributed to data saturation and provided great insight as to what makes a neonatal nurse successful at individualizing patient care, promoting a positive family experience, and encouraging a collaborative approach. This study identified two themes—DSC and FCC—each with its own respective interventions that, when used in conjunction, encourage IFCC. Data from the research contributed to the development of the IFCC Care Model that represents the close relationship between these concepts (See Figure 1). Additionally, the research has identified several important ideas for future consideration by nursing staff in the NICU. The findings of this study can be of benefit to current and future NICU nurses, as well as researchers for future studies. It is my hope that the impact of this study will prompt further research to make IFCC a priority in all facilities with a NICU, and ultimately go on to pave the way for more positive outcomes for critically ill neonates.

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Appendices

Appendix A: List of Abbreviations and Definitions

ABG: Arterial blood gases

APN: Advanced Practice Nurse

BSN: Bachelor of Science in Nursing

CPAP: Continuous positive airway pressure

CXR: Chest x-ray

DSC: Developmentally supportive care

ECHO: Echocardiogram

ET/ETT: Endotracheal/Endotracheal tube

FCC: Family-centered care

HFNC: High-flow nasal cannula

IFCC: Individualized family-centered care

IRB: Institutional Review Board

MSN: Master of Science in Nursing

MV: Mechanical ventilation

NICU: Neonatal Intensive Care Unit

NIPPV: Nasal intermittent positive pressure ventilation

NNP: Neonatal Nurse Practitioner

NRDS: Neonatal Respiratory Distress Syndrome

PaO₂: Partial pressure of oxygen in arterial blood

RN: Registered nurse

RT: Respiratory therapist

SpO₂: Oxygen saturation

Alveoli: very small air sacs in the lungs that are responsible for gas exchange

Amniocentesis: a procedure sampling amniotic fluid using a needle inserted into the uterus to screen for developmental abnormalities in a fetus.

Arterial blood gas analysis: test to assess the blood's pH, oxygen, and carbon dioxide levels to determine if the body is in a state of respiratory or metabolic acidosis or alkalosis

Atelectasis: partial or complete collapse of the lung

Cyanosis: bluish discoloration of the skin resulting from poor circulation or inadequate oxygenation of the blood

Hypoventilation: abnormal finding where the respiratory rate is less than 30 breaths per minute

Hypoxemia: an abnormal concentration of oxygen in the blood

Hypoxia: an abnormal concentration of oxygen in the tissues

Metabolic/Respiratory acidosis: complication that results in excessive acid in the body fluids

Neonate: a newborn infant less than four weeks of age

Oxygenation: the process of delivering oxygen from the alveoli to the tissues

Pneumonia: lung inflammation caused by a bacterial or viral infection

Pulmonary hypertension: a condition where high blood pressure affects the arteries in the lungs and the right side of the heart

Sepsis: a life-threatening response to severe infection where the body damages its own tissues

Surfactant: a substance that coats the lining of lung alveoli, thereby reducing surface tension and allowing gas exchange

Tachypnea: abnormally rapid breathing

Ventilation: the movement of carbon dioxide and oxygen in and out of the alveoli

Appendix B: Defining Neonatal Respiratory Distress Syndrome (NRDS)

Neonatal nurses are required to demonstrate competence and understanding of fetal development, etiology and pathophysiology of NRDS, and how to treat manifestations and prevent complications. The following information is a deeper review of the defining characteristics of NRDS and can be utilized to further understand the implications of this study's results.

Fetal Lung Development and Surfactant Production

Fetal lung development and surfactant production are key concepts in understanding the root causes and treatments of NRDS. The primary etiology of this condition is surfactant deficiency, which occurs when immature lungs fail to produce enough surfactant (Yadav et al., 2021). The less formed the lungs are, the smaller the amount of surfactant available, and the more severe respiratory distress the neonate will experience.

Early in the embryonic stage of pregnancy, the fetus begins to lay the groundwork for what will hopefully become viable gas exchange. The embryo is initially a cluster of mesenchyme, and it is from there that the lung bud first appears as an extension of the esophagus at 26 days following conception (Herriges and Morrisey, 2014). By 37 days, pulmonary vasculature and the mainstem bronchi are formed, with its subsegments developing by 48 days. Between the 5th and 16th weeks of gestation, the airways continue to branch and neuroepithelial cells, cartilage, ciliated cells, goblet cells, and basal cells grow in the proximal pulmonary epithelium. Through the 16th and 25th weeks of pregnancy, the fetus begins to solidify the foundation that will later allow for gas exchange. Lung capillaries continue to grow in number and size. The pulmonary acinus,

blood-air barrier, and cells who will later be responsible for surfactant production begin to form and develop during this stage as well.

Current research shows that a premature infant's earliest potential for viability in extrauterine life may be between 20- and 25-weeks' gestation and is dependent upon obstetric and neonatal management (Raju et. al, 2014). Between the 24th week to the 32nd week, respiratory bronchioles grow a wall thick enough to allow gas exchange (Copland & Post, 2004). During these early weeks in the third trimester of pregnancy, crucial development occurs. The alveoli begin to form and fill with fetal lung fluid as bronchioles further develop, which increases the surface area available for gas exchange. These alveoli play an important role with surfactant and continue to grow and multiply until term.

Surfactant is a necessary substance that works to keep the air sacs in the lungs inflated by covering the inner lining of alveoli and decreasing the surface tension on the small airways (Yadav et al., 2021). Without surfactant, alveoli will collapse, and interstitial fluid will enter the airspace. Its production begins at 20 weeks' gestation in the alveolar cells and begins to largely increase around 32 weeks. Fetal alveoli are filled with amniotic fluid until birth and have a limited supply of surfactant until the later stages of pregnancy—usually the 35th or 36th week (Whitsett & Alenshat, 2014). In the moments following delivery, surfactant plays an important role in helping the newborn breath independently as fluid is cleared from the lungs. If a fetus is born prematurely before it has the chance to develop appropriate amounts of surfactant, respiratory distress is likely to occur.

Etiology and Pathophysiology

Disturbance in fetal lung evolution and surfactant production or activation is largely responsible for the development of NRDS. The most common cause for this condition is prematurity, and as such, it is its primary risk factor. Many obstetric complications and emergencies may place the fetus at greater risk for preterm delivery and increase its risk for NRDS. These include but are not limited to maternal diabetes, maternal drug and/or alcohol abuse, perinatal hypoxia and ischemia, meconium aspiration, hypertensive disorders of pregnancy (preeclampsia and eclampsia), and placental abnormalities (Stylianou-Riga et al., 2021). Additionally, a neonate may show signs of respiratory distress because of neonatal sepsis or as a comorbidity to cardiac or nervous system deformities (Gould et. al, 2022). In other cases, the neonate's airway may not be properly formed and prevent appropriate air exchange. Other risk factors include very low birth weight infants, which can even affect those born at term, and possibly a genetic component for infants of white race and/or male gender.

Signs and Symptoms

There are several signs and symptoms that nurses and providers can expect to see in varying levels of severity when a neonate presents with NRDS. Initial presentation may include decreased breath sounds, oxygen saturation less than 93%, and non-reassuring Apgar scores (further elaborated in Appendix C). Upon further examination or worsening condition, these patients will display increased work of breathing through tachypnea, expiratory grunting, nasal flaring, retractions, use of accessory muscles, central cyanosis, and inadequate peripheral perfusion (Reuter et al., 2014). The most frequent indicators are the use of accessory muscles and noisy breathing or grunting.

Comorbidities and Side Effects

Impaired gas exchange may lead to prolonged respiratory distress, which can cause both short- and long-term complications. If left untreated, the patient's condition will continue to significantly worsen over the following 48 to 72 hours (Reuter et al., 2014). They will begin to display signs of lethargy, apnea, atelectasis, and may develop respiratory acidosis. Treatment in its late stages or prolonged respiratory support can also result in lung damage or other comorbidities. Ultimately, this condition will lead to respiratory failure and neonatal mortality unless promptly addressed.

An oxygen saturation (SpO₂) level less than 93% for an extended period of time indicates that the neonate is not adequately oxygenating the rest of its body and can result in brain damage or other organ failure (Yadav et al., 2021). Although those complications can be addressed, they are not always reversible, and the patient may have long-term medical conditions that affect development or quality of life as a result. Additional complications that the neonate is at risk for are pulmonary leak disorders, interstitial lung disease, bronchopulmonary dysplasia, and neonatal pneumonia or other infections leading to sepsis.

Appendix C: Clinical Practice Guidelines for NRDS

The following information expands upon points mentioned in the literature review and discussion, and explains considerations taken and tasks performed by NNPs and RNs. Clinical practice guidelines may vary based on the facility, and this information may not be considered absolute.

Diagnostic Measures

In the minutes following birth, NICU nurses and providers can often identify signs of neonatal respiratory distress by doing a quick evaluation of the newborn while still in the delivery room. As part of the newborn assessment, neonates are assessed and given an APGAR score ranging from 0 to 10 at one- and five-minute intervals post-delivery (Figure 3). A score between 7 and 10 is considered reassuring, while low scores in the appearance and respiration categories indicate respiratory or other hemodynamic difficulty and require intervention (Simon et al., 2022). In between the two assessments, the NICU care team provides respiratory support and monitors oxygen levels with hopes of raising the APGAR score and encouraging the infant to breathe independently. Other telltale signs and symptoms of NRDS that they are monitoring for are the use of accessory muscles, grunting or noisy breathing, tachypnea, and cyanosis of the lips and face (Reuter et al., 2014).

Figure 3: APGAR Scoring System

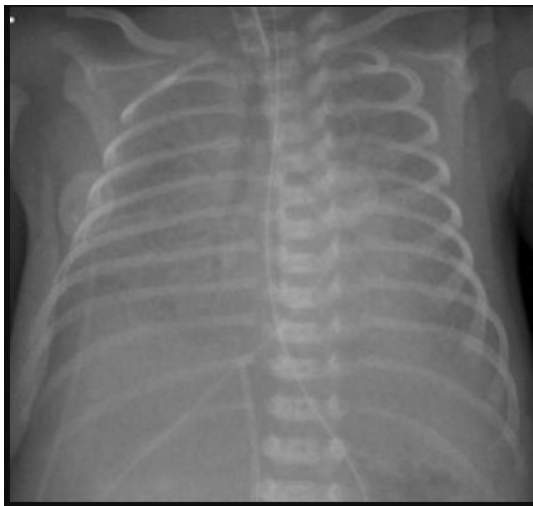
| TABLE 15.4 Apgar Score* | | | | POINTS | | | | | | |
|------------------------------|--|---|--|--------|---|---|---|---|---|----|
| Assessment | 0 | 1 | 2 | | | | | | | |
| Heart rate | Absent | Below 100 beats per minute (bpm) | 100 bpm or higher | | | | | | | |
| Respiratory effort | No spontaneous respirations | Slow respirations or weak cry | Spontaneous respirations with strong, lusty cry | | | | | | | |
| Muscle tone | Limp | Minimal flexion of extremities; sluggish movement | Flexed body posture; spontaneous and vigorous movement | | | | | | | |
| Reflex response | No response to suction or gentle slap on soles | Minimal response (grimace) to suction or gentle slap on soles | Responds promptly to suction or gentle slap to sole with cry or active movement | | | | | | | |
| Color | Pallor or cyanosis | Bluish hands and feet only (acrocyanosis) | Pink (light skinned) or absence of cyanosis (dark skinned); pink mucous membranes | | | | | | | |
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| Infant needs resuscitation.† | | | Gently stimulate by rubbing infant's back while administering oxygen. Determine whether mother received narcotics, which may have depressed infant's respirations. | | | | Provide no action other than support of infant's spontaneous efforts and continued observation. | | | |

Note. From *Foundations of Maternal-Newborn and Women's Health Nursing* (p. 420), by S. Murray et al., 2018. Copyright 2018 by Saunders.

If the newborn fails to maintain oxygen levels while breathing independently, transfer to the NICU will be necessary. There, the team will monitor the patient's vital signs, pay careful attention to its oxygen and ventilation status, and determine what plan of action needs to take place. Further diagnostic testing may be ordered to provide a clearer picture of the neonate's lung function. Arterial Blood Gas (ABG) analysis is often performed by drawing blood an indwelling arterial line in patients who require frequent assessment but may also be obtained through intermittent venipuncture of a peripheral artery. The results show the patient's current ventilation and perfusion status and help determine its acid-base balance. Neonatologists and NNPs look to see if the values are indicative of hypoxemia and respiratory and metabolic acidosis, which are common

complications that will require treatment. Other diagnostic tests that may be ordered include an echocardiogram (ECHO), chest x-ray (CXR), complete blood count (CBC), and blood, cerebrospinal fluid, and tracheal cultures (Yadav et al., 2021). CXR remains a popular choice and will display a ground glass appearance across the anterior lung fields (atelectasis) for patients with NRDS (El-Malah et al., 2015). Repeat orders for these tests may be used to monitor progress in the neonate's condition.

Figure 4: *CXR of NRDS*²



Note. From “*Lung ultrasonography in evaluation of neonatal respiratory distress syndrome,*” by H. E. El-Malah et al., 2015, *The Egyptian Journal of Radiology and Nuclear Medicine*, 46, p. 470. Copyright 2015 by The Authors.

Clinical Management and Treatment Plan

Preventing the occurrence of NRDS is always the ideal treatment. In situations where the healthcare team is expecting a preterm delivery, labor will ideally be prolonged by at least 48 hours so that antenatal corticosteroids (betamethasone and dexamethasone) can be administered to speed lung development (ACOG, 2021). Careful monitoring of the fetus' heart rate prior to and during labor will also provide the team with information

about its oxygenation status. When these measures fail to prevent the development of NRDS, optimal management includes utilizing respiratory support, surfactant therapy, and supportive care of the premature infant using an IFCC approach.

Around the clock monitoring of oxygen and ventilation status is essential for these patients, as their condition can take a turn for the worse in a matter of minutes.

Noninvasive pulse oximetry measures the oxygen saturation in the patient's blood, which is a strong indicator of respiratory status. After obtaining a blood specimen for ABG analysis, special attention will be paid to the partial pressure of oxygen (PaO₂) value that measures oxygen pressure in arterial blood. There is a need for further research to identify and support ideal target ranges for neonatal hemoglobin oxygen saturation (SpO₂) levels in neonates receiving oxygen therapy. Castillo et al. (2008) conducted a study at Emory University and concluded that SpO₂ levels greater than 93% encouraged PaO₂ levels greater than 80 mm Hg, when compared to neonates who maintained SpO₂ values of 85% to 93%. Acceptable ranges vary based on each facility's policy and are often analyzed on a case-by-case situation.

Respiratory support aids in the stabilization of the newborn in the moments following birth and can be utilized as part of the patient's plan of care as their lungs continue to develop in the safety of the NICU. Common options include the use of continuous positive airway pressure (CPAP), nasal intermittent positive pressure ventilation (NIPPV), high-flow nasal cannulas (HFNC), and endotracheal (ET) intubation/mechanical ventilation (MV) (Yadav et al., 2021). Of these options, those considered minimally invasive are nasal and bubble CPAP, NIPPV, and HFNC. ET intubation is much more invasive and involves the insertion of an endotracheal tube

(ETT) inside the mouth and through the windpipe, which is connected to a machine that will mechanically ventilate the patient. Preterm neonates showing signs of respiratory distress without improvement may be intubated via ETT in the moments following their birth. Moya et al. (2019) reported that 74% of neonates born at 26-28 weeks' gestation and 33% of neonates born at 29-32 weeks' gestation required ET intubation within 15 minutes to three hours following delivery.

Although respiratory support offers the neonate the necessary aid to adequately perfuse body tissues, it does not do so without risks. Recent studies recommend initiating the least invasive respiratory support option before resorting to MV (Cannavò et al., 2020). Prolonged MV can give the patient a higher chance of brain injury leading to cognitive and behavior deficits (Polgase et al., 2014)) and is associated with increased dependency (Sauthier et al., 2021). The neonate's healthcare team must tether the fine line of offering respiratory support without encouraging the patient to be dependent on it.

As previously mentioned, surfactant deficiency is the primary cause of NRDS in the preterm neonate. A highly recognized and effective treatment for this is surfactant replacement therapy, which involves the administration of natural or artificial surfactant through an ETT. It is indicated in neonates with clinical and radiographic evidence of RDS (Eda, 2021). There are three natural surfactants, all derived from animal sources, that are frequently used: poractant (Curosurf), beractant (Surcanta), and calfactant (Infasurf) (Cheng-Hwa Ma & Ma, 2012). Palmitate (Exosurf) and licinactant (Surfaxin) are two synthetic surfactants that are increasing in popularity and use. Either type of surfactant may be used based on the provider's preference, and there is current debate on

which may be more beneficial in the treatment of NRDS. More research is needed to define the benefits and risks of using each.

Surfactant administration is considered an invasive procedure because it is administered through the ETT, which helps the medication reach the alveoli of the lungs. If the patient is not already intubated, a temporary in-and-out intubation will be performed. Recently, studies about minimally invasive surfactant therapy have begun to emerge, but more data is needed to explore its effectiveness and potential risks and side effects. The procedure requires at least one NNP or licensed medical practitioner to administer the surfactant and one RN to assist. It is performed using surgical aseptic technique, due to the high risk of infection. The RN will disconnect the ETT from the ventilator, if applicable, while the NNP draws up the correct dose. Dosing information may be referenced through a medication resource, such as Lexicomp. The neonate will lie in a supine position while the NNP gives a bolus dose through the distal end of the ETT, as the patient tolerates, which is usually over one minute or less. This allows the medication to reach the alveoli of the lungs. Afterwards, invasive (MV) or noninvasive (CPAP) respiratory support may be increased temporarily and the NNP will stay with the neonate until they are stable. Pulmonary vital signs will be monitored closely to determine this and repeat ABGs may be ordered to assess for improvement.

Pharmacologic treatment of NRDS may also include medications to prevent or address comorbidities. Antibiotic support with drugs like vancomycin or azithromycin can be prescribed to prevent or treat respiratory infections, specifically pneumonia, that may later lead to neonatal sepsis (Hsieh et al., 2014). Medications to support blood pressure and cardiac function, such as milrinone and sildenafil, can improve pulmonary

hypertension. Additionally, midazolam and fentanyl can be prescribed for pain or sedation.

Nursing Care for NRDS

Nursing care for patients with NRDS includes numerous hands-on skills and interventions, as well as communicative and collaborative measures. The responsibilities of a NICU nurse are used on a case-by-case basis and will not all be performed with every patient. These responsibilities include, but are not limited to: administering medications, drawing labs, monitoring vital signs, giving respiratory support, maintaining a developmentally supportive and therapeutic environment, diaper changes, bathing, feeding, comforting the patient and family, a collaborating with the healthcare team. NRDS is often accompanied by additional diagnoses, and nurses are also responsible for preventing and monitoring for those complications.

It is necessary for NICU nurses to provide constant therapeutic communication with the families of their patients. The NICU can be an overwhelming environment for those who are not familiar with it, and neonates with NRDS may be unable to be held or fed for extended periods of time. This can be deeply upsetting for the parents, and nurses must be prepared to intervene to provide support and advocacy for the parents and neonate. Additionally, they can expect to communicate and collaborate with a variety of healthcare professionals, such as RTs, occupational therapists, physical therapists, pharmacists, neonatologists, pediatricians, social workers, and more.

NNPs may utilize their prior experience as a NICU nurse to tailor their care to benefit the patient and family. They are responsible for overseeing and directing the plan of care for a number of patients and will work closely with a neonatologist. They are

licensed to provide additional care for a patient with NRDS, which can include intubation, placing a central line, and lumbar punctures; however, it is important to note that their exact scope of practice will vary depending on their state's regulations.

Appendix D: Copy of IRB Approval Form

IRB
INSTITUTIONAL REVIEW BOARD
 Office of Research Compliance,
 010A Sam Ingram Building,
 2269 Middle Tennessee Blvd
 Murfreesboro, TN 37129
 FWA: 00005331/IRB Regn. 0003571



IRBN001 - EXPEDITED PROTOCOL APPROVAL NOTICE

Thursday, December 09, 2021

Protocol Title **The Nurse's Rule in the Care of Neonates Diagnosed with Diagnosed with Neonated Respiratory Distress Syndrome using an Individualized Family-Centered Care Approach**

Protocol ID **22-2066 7v**

Principal Investigator **Natalie Young** (Student) **Faculty Advisor:** Amanda Flagg

Co-Investigators NONE

Investigator Email(s) ncy2b@mtmail.mtsu.edu; Amanda.flagg@mtsu.edu

Department School of Nursing

Funding NONE

Dear Investigator(s),

The above identified research proposal has been reviewed by the MTSU IRB through the **EXPEDITED** mechanism under 45 CFR 46.110 and 21 CFR 56.110 within the category (7) *Research on individual or group characteristics or behavior*. A summary of the IRB action is tabulated below:

| | | | |
|----------------------------|--|----------------------------------|-------------------------------|
| IRB Action | APPROVED for ONE YEAR | | |
| Date of Expiration | 12/31/2022 | Date of Approval: 12/9/21 | Recent Amendment: NONE |
| Sample Size | TEN (10) | | |
| Participant Pool | Target Population: Primary Classification: General Adults (18 or older) Specific Classification: Registered Nurses with BSN | | |
| Type of Interaction | <input type="checkbox"/> Non-interventional or Data Analysis <input checked="" type="checkbox"/> Virtual/Remote/Online interaction <input type="checkbox"/> In person or physical interaction – Mandatory COVID-19 Management | | |
| Exceptions | 1. Voice recording is permitted. 2. Verbal consent via Zoom or telephone is allowed. | | |
| Restrictions | 1. Mandatory ACTIVE Informed Consent. 2. Other than the exceptions above, identifiable data/artifacts, such as, audio/video data, photographs, handwriting samples, personal address, driving records, social security number, and etc., MUST NOT be collected. Recorded identifiable information must be deidentified as described in the protocol. 3. Mandatory Final report (refer last page). | | |
| Approved Templates | IRB Templates: IRB Recruitment Flyer and Zoom Informed Consent Non-MTSU Templates: Telephone Informed Consent and NICU Flyer | | |
| Research Inducement | NONE | | |
| Comments | NONE | | |

Appendix E Copy of Informed Consent

IRB

INSTITUTIONAL REVIEW BOARD
Office of Research Compliance,
010A Sam Ingram Building,
2269 Middle Tennessee Blvd
Murfreesboro, TN 37129



IRBF030 – Zoom Interview Informed Consent for Expedited Protocols INFORMATION AND DISCLOSURE SEGMENT (Part A. Participant Copy)

Study Title The Nurse's Role in the care of neonates diagnosed with Neonatal Respiratory Distress Syndrome using an Individualized Family-Centered Care Approach

Primary Investigator(s) Natalie Young *Student*

Faculty Advisor Dr. Amanda Flagg

Department & College MTSU SON

Contact information ncy2b@mtmail.mtsu.edu

IRB ID 22-2066 7v *Approval:* 11/24/2021 *Expiration:* 11/30/2023

The following information is provided to inform you about the research project in which you have been invited to participate. Please read this disclosure and feel free to ask any questions. The investigators must answer all of your questions prior to your participation and you must be given a signed copy of this disclosure.

- Your participation in this research study is voluntary.
- You are free to withdraw from this study at any time without loss of any benefits.
- In the event new information becomes available that may affect the risks or benefits associated with this research study, you will be notified so that you can make an informed decision at that time.

For additional information on your rights as a participant in this study, please contact the MTSU Research Compliance (Tel 615-494-8918 or send your emails to irb_information@mtsu.edu, (URL: <http://www.mtsu.edu/irb>).

Please read this section and retain this for future reference. Once you have completed reading this section, please give consent as directed in the end of this document if you wish to enroll.

1. What are the prime types of physical contact the participant will have?
The participant will have the following type(s) of contact(s) with the investigators or/and other participants at least sometimes during this research:
 1.1 Virtual Interactions
 Qualtrics Zoom Telephone Other
 1.2 In person interactions NONE
2. What is the main category of this research?
 2.1 Educational Tests 2.2 Social/Behavioral Evaluation
 2.3 Psychological intervention or procedures 2.4 Physical Evaluation or Procedures
 2.5 Medical Evaluation 2.6 Clinical Research
3. What is the purpose of this study?
The purpose of this study is to explore the use of Individualized Family-Centered Care in NICU nurses' care plans resulting in a more positive outcome for their patients diagnosed with Neonatal Respiratory Distress Syndrome.

Appendix F: Copy of IRB Approved Flyer

Research Participants Needed

Study Title: The Nurse's Role in the care of neonates diagnosed with Neonatal Respiratory Distress Syndrome using an Individualized Family-Centered Care Approach
Protocol ID 22-2066 7v Approval 11-24-2021 Expiration 11-30-2023

Study Description & Purpose

This is a pilot qualitative study looking to explore the use of Individualized Family-Centered Care (IFCC) in NICU nurses' care plans for their patients diagnosed with Neonatal Respiratory Distress Syndrome (NRDS). Qualified participants will commit to one 60 minute interview via telephone or zoom (video off) and be asked a series of questions related to the experience in using IFCC in their patients with NRDS.

Target Population

We are looking for participants with their RN, B.S.N. who have 1-15 years of experience working in a Level III or IV Neonatal Intensive Care Unit.

Risk & Benefits

There are no direct risks or benefits for participants of this study.

Additional Information

All participation is voluntary and participants will not receive compensation. Participants' identities will be kept confidential.

Contact Information

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Institutional Review Board, Middle Tennessee State University
2269 Middle Tennessee Blvd, Room 010A, Murfreesboro, TN 37132
Tel 615 494 8918 | Email: irb_information@mtsu.edu | www.mtsu.edu/irb

Appendix G: Copy of Interview Questions

1. Will you state your licensure and number of years of experience working in a level III or IV NICU?
2. Describe key aspects of care you provide for a patient with NRDS (nursing interventions, clinical practice guidelines, communication with family, etc.).
 - a. What interventions might you see for pain management in these infants?
 - b. In what ways are you able or unable to involve the family when implementing your care/interventions for these patients?
3. How does the care you provide differ based on the age of the neonate (born earlier than or later than 32 weeks gestation)?
4. How do you advocate for your patient under their circumstances (born at or earlier than 32 weeks, diagnosed with NRDS, too young to communicate needs)?
5. In your practice, how do you individualize the concept of Family-Centered Care? How would you define Individualized Family-Centered Care?
6. In your experience, what protocol(s) are in place to guide your care of the patient with NRDS as you feel it relates to Individualized Family-Centered Care? What part of the protocol (if there is one) do you find most and/or least helpful when caring for patients with NRDS?
7. How much of a positive or negative impact do you think involving the family brings?

(For NICU nurses with 10-15+ years of experience)

8. What do you notice about newer NICU nurses who come to the unit with little to no NICU exposure when caring for patients with NRDS?
9. What changes have you noticed since the start of your career in the treatment of NRDS and the use of family-centered care?
 - a. Have these changes resulted in more positive or negative outcomes overall?

(For NICU nurses with less than 5 years of experience)

10. How much NICU education/training did you receive regarding family-centered care before working in the NICU?