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Eastern Kentucky University

Family Centered Care in the Neonatal Intensive Care Unit:

A Standard Checklist for Nurses and Parents

Honors Thesis

Submitted

In Partial Fulfillment

Of The

Requirements of HON 420

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By

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Faculty Mentor

Dr. David Coffey

School of Nursing

Abstract

Neonatal Intensive Care Units (NICUs) care for critically ill newborn babies. Family Centered Care (FCC) is a relatively new standard of NICU care that allows for caregivers to be as much of a part of the NICU experience as health care providers. This thesis utilized a review of literature to identify research that shows that FCC is an effective way to improve outcomes for neonates and their caregivers. Many sources did provide evidence for this. Some evidence shows that FCC can lead to shorter length of stay, increased rates of breastfeeding, and increased weight gain for the neonates, while parents/caregivers see increased bonding and parent-infant attachment and decreased stress and anxiety. An additional review of literature identified specific evidence-based interventions that work with FCC. However, there is no standardized way for NICU staff (namely nurses) to implement all of these aspects of FCC that are shown to be conducive to improved outcomes. For this thesis, a standard checklist, composed of evidence-based FCC interventions (including communication, parent education, empowerment, basic infant care, breastfeeding, private rooms, bonding, and technology), was created to streamline the process of FCC in the NICU. The utilization of this checklist will help nurses and parents to ensure their neonate is benefitting from their care.

Keywords: neonatal intensive care unit, family centered care, nurses, parents, checklist, bonding, parent education

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Family Centered Care Checklist

- Communication
 - Parents spoke with staff today
 - Questions answered appropriately
 - Communication was therapeutic and effective
- Parent Education
 - Parents were instructed on what to expect in the NICU upon admission
 - Follow-up evaluation conducted and questions answered
- Empowerment
 - Parents participated in an empowerment program upon admission
 - Follow-up evaluation conducted and questions answered
- Basic Care
 - Parents participated in at least one basic care session today
 - Parents performed the following skills (circle all that apply): diapering, feeding, swaddling, bathing, medication administration, other: _____
- Breastfeeding
 - Baby received breastmilk today
 - Via: tube feeding, bottle, breast (circle one)
 - From: birthing parent, donor/milk bank (circle one)
- Private Rooms
 - Unit has private rooms available
 - Parents have utilized space available in the room to store personal items
- Bonding

- Baby was held skin-to-skin for at least 1 hour today by a parent
- Technology
 - Room is equipped with a web camera
 - Caregivers have been oriented to technology in the room
 - If parents are not present in person today – parents have checked in via the livestream today

Family Centered Care in the Neonatal Intensive Care Unit: A Standard Checklist for Nurses and Parents

Background & Significance

Intensive care is a medical specialty in which patients in critical condition are cared for. Intensive care units (ICU) are sometimes specialized by body system, such as neurologic intensive care for the brain or cardiac intensive care for the heart. There is one very special subsection of ICUs that cares specifically for newborn babies, or neonates. One common cause of a neonate being admitted to intensive care is preterm birth. Preterm births have a high incidence rate in the United States, and especially in Kentucky. According to the Center for Disease Control and Prevention (2022), Kentucky has the 9th highest preterm birth rate in the United States (US) with approximately 11.05 preterm births (defined as a child being born prior to 37 weeks' gestation) occurring for every 1,000 births.

While the exact cause of preterm birth is not known, as it can vary greatly from pregnancy to pregnancy, many studies have identified various risk factors that can increase the possibility of preterm birth. In undeveloped and underdeveloped countries

(specifically in Asia and Africa), preterm birth is typically associated with maternal age under 20 years, lack of formal education, little-to-no prenatal care (including the absence of antenatal iron, prenatal vitamins, and calcium), pregnancy complications including hemorrhage and gestational hypertension, and fetal malpresentation (Pusdekar et al., 2020).

Preterm birth rates vary from state to state in the US, with Kentucky being in the top 10 for most preterm births per capita. There are risk factors that are more prevalent in some states that have been identified to increase this incidence. For example, pregnant people of color (specifically non-Hispanic Black people) are at the highest risk due to being more likely to fit many of the risk factors (Bublitz et al., 2020). In the United States, preterm birth rates are higher in states with increased poverty rates, obesity rates, percentage of non-Hispanic Black female residents, smoking rates, cesarean delivery rates, percentage of births to pregnant people younger than 20 years old, pregnancies receiving late or no prenatal care, and rates of violent crimes per capita (Bublitz et al., 2020).

While preterm births are higher in underdeveloped countries, the United States has one of the highest rates of preterm births among developed countries (Centers for Disease Control and Prevention, 2022). This is likely related to the fact that the US is the only developed nation in the world that does not have free primary and/or universal healthcare or is not currently working towards implementing it (World Health Organization, 2022). Despite pregnant people being eligible for Medicaid and other government assistance, many are not educated on this or choose not to take advantage of

it which puts them at higher risk for preterm birth, pregnancy complications, and other issues (Bublitz et al., 2020 & Franck et al., 2020).

According to Franck et al., there are some primary and secondary prevention strategies that can decrease the incidence of preterm birth (2020). These include diet education, access to and education on prenatal care, screening and treatment for sexually transmitted infections (STIs), early identification and treatment of pre-eclampsia, and interventions to compensate for cervical insufficiency (Franck et al., 2020). However, there are deeper systemic issues in the US that increase the incidence of preterm birth that cannot be repaired at the individual level even with widespread implementation of clinical trials (Franck et al., 2020). So, the high preterm birth rate will likely remain high in the US for a long time to come. While the preterm birth epidemic continues, a disproportionate number of babies will be born prematurely and remain at high risk for complications and death. Because of this, these infants need specialized care after birth.

Neonatal Intensive Care Units (NICUs) house and care for one of the most vulnerable patient populations in health care: premature and/or critically ill newborn babies. These infants' lives are extremely fragile, with some being born at as little as 22 weeks' gestational age and as small as 245 grams (about half of a pound) (Lee et al., 2016). They are at increased risk of life-threatening septic infections, breathing problems, bleeding in the brain, issues with multiple major organs such as the heart, liver, intestines, eyes, blood vessels, and more (Yu et al., 2017). These patients may spend days, weeks, or months hospitalized in the NICU until they are able to eat and gain weight, regulate their own temperature, and breathe on their own which is much, but this is no simple feat for

newborns who have made it barely past half of their intended fetal development (Lee et al., 2016).

One such example of a difficult feat for neonates is overcoming breathing issues. This takes a lot of work for the neonate and the NICU staff. Premature infants are at high risk for respiratory distress syndrome (RDS). This is often due to a combination of structurally underdeveloped lungs and insufficient surfactant production (Gregorio-Hernandez et al., 2020). Surfactant is the substance that decreases surface tension in the lungs, prevents the lungs from collapsing, and allows for ease of breathing. Without enough surfactant or working lungs, premature infants are at high risk for RDS (Gregorio-Hernandez et al., 2020). Effective treatment for RDS can be invasive, dangerous, and has the potential to lead to death. Preterm infants with RDS often require mechanical ventilation and other interventions that are hard on their bodies (Gregorio-Hernandez et al., 2020).

NICUs have a lengthy history. According to Payne (2016), the modern NICU was first created in the 1950s-1970s, but the “pre-NICU era” began as early as the seventeenth century when doctors and scientists began conducting research on preterm infants. Since then, many advances have been made in the field of neonatal care, including the integration of different levels of care. According to the American Academy of Pediatrics (AAP) (2012), providing a standardized definition and organization for different levels of neonatal care leads to improved neonatal outcomes. Until 2012, NICUs were organized into 3 levels in the United States, but the AAP Committee on Fetus and Newborn created a new policy, based on a review of data-supported evidence, further organizing NICUs into four levels (2012).

According to the AAP's report, a Level I NICU, is a standard well-baby nursery that can be found in any hospital with a Labor and Delivery unit (2012). Staff in these NICUs will provide "low risk" (American Academy of Pediatrics, 2012, p.592) care for babies born no earlier than 35 weeks' gestation, they can perform neonatal resuscitation, assess and provide care to stable newborns born at term (at least 37 weeks), stabilize and provide care for infants born 35-37 weeks who are physiologically stable, and stabilize newborn infants who are acutely ill and/or born earlier than 35 weeks until they can be transferred to a higher level of care (American Academy of Pediatrics, 2012). Provider types in a Level I NICU include "pediatricians, family physicians, nurse practitioners, and other advanced practice registered nurses," (American Academy of Pediatrics, 2012, p.592).

Level II NICUs are considered specialty level nurseries. Level II NICUs will provide all the same care as Level I NICUs as well as care for neonates born at a minimum of 32 weeks' gestation who weigh at least 1500 grams (American Academy of Pediatrics, 2012). Care at this level is reserved for stable or moderately ill neonates. Whatever physiological problems these babies have are expected to be fixed quickly. No infants at this level of care should urgently require sub-specialty care, such as anesthesiology, neurology, or cardiology. Level II NICUs can provide transitional care for infants who previously received care in a higher level of NICU. They can provide brief mechanical ventilation (intubation) for a period of less than 24 hours, as well as external oxygenation such as continuous positive airway pressure (CPAP). They can also briefly stabilize infants that do not meet their admitting requirements until they can be transferred to a higher level of care. Providers in Level II NICUs include all those

available in Level I, as well as pediatric hospitalists, neonatologists, and neonatal nurse practitioners (American Academy of Pediatrics, 2012).

Level III NICUs are able to provide all the same care as Level I and II NICUs, but they can also provide sustained life support, comprehensive care for infants born under 32 weeks' gestation and weighing less than 1500 grams, they have many subspecialty care team members, including pediatric medical specialists, pediatric surgical specialists, pediatric anesthesiologists, and pediatric ophthalmologists (American Academy of Pediatrics, 2012). Level III NICUs can also provide all types of respiratory support that may be necessary for neonates with compromised lungs (American Academy of Pediatrics, 2012). Level III NICUs also have the capability to run imaging tests (such as MRIs or CT scans) and interpret the results of these tests “on an advanced basis” (American Academy of Pediatrics, 2012, p.592). Level IIIs have the same providers as Level Is and IIs plus the subspecialty care providers listed previously.

Level IV NICUs are known as regional NICUs. They are very similar to Level III NICUs in the level of care that they are able to provide, but Level IVs are located within a hospital that provides access to complex medical and surgical care, such as the ability to repair congenital birth defects (American Academy of Pediatrics, 2012). The institutions that house Level IV NICUs are also typically the ones to do the most research within the neonatal specialty, including the utilization of Family Centered Care.

Family Centered Care (FCC) is a relatively new facet of NICU care. FCC has been a standard of care in Neonatal Intensive Care Units since about 1992 (Neu et al., 2020). According to Deepika and Rahman, Family Centered Care is “...an approach to the planning, delivery, and evaluation of health care that is grounded in mutually

beneficial partnerships among health care providers, patients, and families,” (2020, p.43). In NICUs that utilize a basic level of FCC, parents can hold, change, bathe, and feed their child (Griffin, 2006). In some higher level NICUs that allow for more FCC, parents may be able to administer medications, help make treatment and care decisions, and even stay in a private room with their baby to assist in round-the-clock care. The evidence shows that utilizing FCC in the NICU leads to decreased parental stress and anxiety and increased growth and development in the patients (Cheng et al., 2021).

Having a child hospitalized in the NICU can be an extremely stressful and scary time for parents, especially for the birthing parent who has just delivered a preterm or sick child and is experiencing postpartum hormones and possibly medical issues themselves (Cheng et al., 2021). Being involved in their child’s care allows the parents to bond with their baby and for postpartum attachment (PPA) which is shown to decrease maternal stress which helps foster the development of the child that NICUs strive for (Kim, Kim, & Yun, 2020).

Some nurses in the NICU, especially those in lower level NICUs, may be unaware of the importance and efficacy of FCC, especially for pediatric patients and their parents. Nurses may focus solely on the patient and getting them healthy. While caring for the physical health of patients is an important facet of nursing care, parental involvement and presence is also critical to the wellbeing of hospitalized children (Zauche et al., 2019). NICUs must allow parents to care for the child to allow for bonding and healing during what is otherwise a traumatic experience (Kim, Kim, & Yun et al., 2020). Additionally, parents may be too nervous to ask to help or worried that they may hurt their already fragile child (Neu et al., 2020). NICU babies often have many

monitoring devices, intravenous (IV) tubing, oxygen delivery devices, and many other medical items near or attached to them. This can be daunting for parents. These devices are what are known as environmental stressors which are one of the biggest causes of fear and anxiety for NICU parents (Kim et al., 2020).

FCC is a crucial component of holistic care. Holistic care is the interest in caring for the patient's entire wellbeing, which for pediatric patients, and NICU babies especially, includes the wellbeing of their parents/caregivers. For the previously stated reasons, NICUs should utilize a Family Centered Care Protocol to ensure they are doing it right and doing it well. This would include many factors, such as the standardization of visiting hours, private rooms, guidelines for parent education, staff training in meeting the emotional needs of parents, teaching parents to be advocates, and more (Franck et al., 2020).

Atul Gawande wrote *The Checklist Manifesto: How to Get Things Done Right* (2011). The theme of the book is that protocols, formed as literal checklists, are the best way to ensure that procedures are followed and done right. Gawande's specific background is as a surgeon, but his research and book indicate that checklists are indispensable for any profession, including pilots and architects. Checklists eliminate the ability to question whether or not something was done and reduce the risk of harm created by missing steps. Many cases of negligence and malpractice in the hospital are due to simple human error, but these errors can be fatal. According to the Institute of Medicine (US) Committee on Quality of Health Care in America, more US citizens die because of medical errors than motor vehicle accidents or breast cancer (Kohn et al., 2000). However, with safer protocols in place, these medical error deaths can be

prevented. That is why almost every specialty of medicine utilizes checklists. Checklists enhance quality of care and patient safety (Gawande, 2011). According the World Health Organization Public Safety department, surgery uses safety checklists and equipment counts to prevent infection and promote adherence to standards of care (2009). Emergency departments also utilize checklists to improve patient safety, such as Redfern et al.'s quality improvement checklist (2018). Similar checklists can be found in the protocols of almost all medical departments in every hospital (Gawande, 2011). NICUs utilize some checklists, but none specifically related to FCC.

Purpose

The purpose of this thesis is to create an evidence-based interventions checklist for NICU nurses to use in order to assure quality of care and patient safety during hospitalization by utilizing family centered care to benefit neonatal patients and their parents.

Review of Literature

This review of literature was conducted to find existing evidence that Family Centered Care is utilized to yield improved outcomes for neonates and decreased parental stress and anxiety. The methods for this literature review included the databases CINAHL, PubMed, and PsycInfo. Keywords used included “family centered care or family centered nursing or family-centered care or family-centered nursing,” “neonatal intensive care unit or NICU or baby unit or newborn intensive care,” and “parental involvement or parent engagement or parent participation.” The search was narrowed to include only peer reviewed research, published within the last 5 years that were available

in English. On CINAHL, this search yielded 21 results, on PubMed there were 14 results, and on PsycInfo there were 5 results. The results were then narrowed by title and then abstract to include only those studies which were relevant to the search. Only quantitative studies were utilized in this review of literature. Of these, five studies were selected for review.

The first of these was an article from O'Brien et al., (2018). Family Integrated Care (FICare) is a standardized version of FCC used mostly outside of the United States. Since this study was conducted outside of the United States (specifically in Canada, Australia, and New Zealand), the NICUs included do not fit directly into the AAP's designated levels of neonatal care (2012). However, the article states that in order for a NICU to be eligible for the study, they must have the capability to care for neonates born at less than 33 weeks' gestation from birth (O'Brien et al., 2020), which is comparable to a Level III NICU in the United States. This was a cluster-randomized control trial that was conducted across 25 NICUs in 3 countries. The researchers provided each site with "a unique, consistent written protocol and printed educational and training material," (O'Brien et al., 2020, p.247) on the standards of Family Integrated Care, however, no specific checklists were utilized. The results of this study concluded that FICare improved weight gain in infants and increased breastfeeding rates, and decreased parental stress and anxiety (O'Brien et al., 2020). This study did not examine long term outcomes for neonates or their families.

The next study chosen was entitled "Effect of a Parent Empowerment Program on Parental Stress, Satisfaction, and Length of Stay in the Neonatal Intensive Care Unit" by Holly Nieves, Alyssa Clements-Hickman, and Claire Davies (2021). This study examined

how providing parents with the encouragement that they need to participate in the care of their hospitalized infant can lead to improved outcomes for both the neonate and their family. This was a quasi-experimental study used to implement the COPE (Creating Opportunities for Parent Empowerment) program (Nieves et al., 2021). The study was conducted in a Level III NICU and the population sample included premature infants born at a minimum of 35 weeks' gestation (Nieves et al., 2021). The intervention of the COPE program included 4 phases of training sessions, including "Helping Your Premature Baby Grow and Develop" completed within a few days of delivery, "Helping Yourself and Your Baby, the Early NICU Days" completed about a week after admission, "Getting Ready to Go Home Together" completed about a week prior to discharge, and "Adjusting to Life at Home With Your Baby" completed over the phone one week after discharge for the NICU (Nieves et al., 2021, p.94). The intervention also included the issuance of a COPE handbook. There was no checklist used for this intervention/study. The results showed that parents reported lower levels of stress and they were satisfied with the COPE program and the NICU stay overall (Nieves et al., 2021). Results from the intervention group also showed decreased length of NICU stay for the babies whose parents had undergone the training (Nieves et al., 2021). Promoting parental empowerment and encouraging participation in care is another example that FCC is a beneficial and evidence-based NICU intervention.

The next study selected was "The effectiveness of a parent participation improvement program for parents on partnership, attachment infant growth in a neonatal intensive care unit: A randomized controlled trial" by Yoo Jin Heo and Won-Oak Oh (2019). The researchers of this study first developed the Parent Participation

Improvement Program and then used a randomized-controlled trial to implement it in a NICU in Seoul, South Korea (Heo & Oh, 2019). Since this study occurred outside of the United States, the NICU involved is not categorized using the AAP's Levels of NICUs (2012). However, the inclusion criteria for this study required that the neonates be born prior to 37 weeks' gestation and require no more invasive respiratory support than a high-flow nasal cannula (meaning no infants requiring mechanical ventilation were included in the study), meaning that the patients included in this research would be comparable to patients in a Level II NICU (Heo & Oh, 2019). This study made no mention of utilizing a checklist in their protocol. The results of this research indicate that parental participation is effective in improving parent/infant attachment and parent/nurse partnerships (Heo & Oh, 2019).

The next study examined in this review was "Family-Centered Care Improves Clinical Outcomes of Very-Low-Birth-Weight Infants: A Quasi-Experimental Study" (Lv et al., 2019). The FCC intervention used in this research was both parental education about basic newborn care as well as a requirement that parents actively care for their hospitalized infant for at least 4 hours a day (Lv et al., 2019). This was a quasi-experimental, quantitative study that took place in China so the researchers did not use the AAP's (2012) categories for Levels of NICUs, however they looked specifically at the data for very-low-birth-weight (VLBW) infants, which are infants born at less than 1500 grams, so this study focused on a patient population comparable to a Level III NICU in the United States. This study did not utilize a checklist in its protocol. The results of this study demonstrated that the FCC intervention led to higher infant weight at discharge, higher rates of breastfeeding and shorter length of total parenteral nutrition

(TPN) or gastric feedings, and decreased rate of complications (including bronchopulmonary dysplasia, retinopathy of prematurity, necrotizing enterocolitis), as well as lower readmission rates (Lv et al., 2019). This is quantitative evidence that FCC is effective at improving neonatal outcomes in the NICU.

The final study examined for this review of the literature was “Family Centered Care Improved Neonatal Medical and Neurobehavioral Outcomes in Preterm Infants: Randomized Controlled Trial” (Yu et al., 2017). The purpose of this study was to replicate the medical innovations of FCC that exist in Western societies in Eastern healthcare systems. This particular randomized controlled trial study took place in Taiwan and the researchers used a family-centered intervention program (FCIP) in the intervention group and a usual care program (UCP) in the control group (Yu et al., 2017). Since this research took place in Taiwan, the NICU used for the study does not fall into one of the AAP’s Levels of NICUs (2012), however, the population used was VLBW infants (babies born at less than 1500 grams) which is comparable to the patient population cared for in Level III NICUs in the United States. This study did not utilize a Family Centered Care checklist. The results of this research showed that FCIP lead to earlier feedings by mouth and earlier discharge, increased weight gain, and better neurobehavioral performance among the infants (Yu et al., 2017). Additionally, the research indicated that parents in the intervention group were more highly motivated, more goal oriented, and more likely to meet their goals than parents in the control group, and the higher rates of these attributes correlated with even higher rates of weight gain and better neurobehavioral outcomes in their child (Yu et al., 2017). This study is further evidence that establishes FCC as a standard of NICU care.

Evidence-Based Interventions

The aforementioned review of literature demonstrates that Family Centered Care is an evidence-based standard of care in the Neonatal Intensive Care Unit. From the literature reviewed, all 5 studies showed that FCC is an effective way to increase positive neonatal outcomes and decrease parental stress and anxiety. However, 0 of the 5 studies utilized a checklist to implement multiple facets of FCC. Based on this review and the evidence discovered, interventions based on quantitative evidence will be evaluated to create the checklist.

After the initial literature review, additional keywords were added to the search criteria to find specific, evidence-based, family centered interventions based on Franck, Waddington, and O'Brien's (2020) article "Family Integrated Care for Preterm Infants" which outlined NICU interventions that can be responsibly performed by parents with the help of nurses. These included "parent education" (1 result on CINAHL, 6 results on PubMed, and 0 results on PsycInfo), "single family rooms or private rooms" (2 results on CINAHL, 1 result on PubMed, and 0 results on PsycInfo), "breast feeding" (3 results on CINAHL, 2 results on PubMed, and 0 results on PsycInfo), "holding or kangaroo care or skin-to-skin" (6 results on CINAHL, 2 results on PubMed, and 1 result on PsycInfo), "basic newborn care or newborn care or basic care" (10 results on CINAHL, 10 results on PubMed, and 2 results on PsycInfo), "nurse-parent communications" (0 results on CINAHL, 1 result on PubMed, and 0 results on PsycInfo), and "technology" (1 result on CINAHL, 1 result on PubMed, and 0 results on PsycInfo). The results were narrowed by title and abstract and to only those studies which were peer-reviewed and written in English.

Communication

The first evidence-based intervention included in this Family Centered Care checklist is effective communication between the family of the infant and the infant's NICU staff, namely their nurses. The rationale for this intervention comes from "Effects of parent-provider communication during infant hospitalization in the NICU on parents: A systematic review with meta-synthesis and narrative synthesis" (Labrie et al., 2021). In this study, "provider" includes all healthcare staff. When parent-provider information is effective, the language makes parents "feel emotionally supported, treated with empathy, and taken seriously," (Labrie et al., 2021, p.1527). Additionally, effective parent-provider communication should "foster collaboration between parents and staff" (Labrie et al., 2021, p.1527). Through this collaboration, parents can know and understand all of the information related to the health and well-being of their child, they can provide providers with consent, and parents can help in the decision-making process for their child's care (Labrie et al., 2021).

The systematic analysis performed for this study reviewed over 5,000 NICU records of parent-provider interactions in Neonatal Intensive Care Units. The records were comprehensively synthesized, and the final ones used in the study included 6,960 parents and their children, 693 providers, and 300 NICUs (Labrie et al., 2021). The results of this analysis revealed 5 common impacts of effective parent-provider communication, these include coping, knowledge, participation, parenting, and satisfaction (Labrie et al., 2021). These effects may be positive or negative, but based on the review, effective communication leads to more positive impacts (Labrie et al., 2021). The studies included in this systematic review included a multitude of tools, but typically

efficacy was measured using self-reported satisfaction scales as well as evaluation of coping skills, knowledge, and participation. Therapeutic communication showed higher levels of these factors and caregivers were more satisfied (Labrie et al., 2021).

Parent-provider communication is most important to the mental well-being of the parents, particularly in decreasing stress and anxiety (Labrie et al., 2021), however, this is an important facet of FCC which is proven to be beneficial to a hospitalized neonate's health. Parent-provider communication is included in FCC because it allows parents to be informed about care as well as actively participate in the decisions for care. Effective parent-provider communication is an effective intervention to add to the FCC checklist as it allows for collaboration, paired decision-making, and improved outcomes.

Parent Education

The next intervention on the checklist is parental education. This intervention includes the utilization of educational training for parents whose child is hospitalized in the NICU. This education is important because it allows parents to learn what to expect from the NICU and how to care for their sick and/or preterm child while they are hospitalized and after they are discharged. One example of this intervention comes from "Family-Centered Care Improves Clinical Outcomes of Very-Low-Birth-Weight Infants: A Quasi-Experimental Study" (Lv et al., 2019). The protocol for this study involved trained nurses "teaching parents the theoretical knowledge of basic care, infant development, hand hygiene, feeding methods, skin-to-skin contact, [and] infection control" (Lv et al., 2019, p.2). After the teaching was completed, parents were supervised by nurses while actively performing these care activities for at least 4 hours a day. This FCC intervention led to improved nutritional outcomes, decreased complications, and

lower readmission rates (Lv et al., 2019). The conclusion of the study is the same as the reason for its addition to the FCC checklist: the evidence shows that when parents are present and actively caring for their child in the NICU, the child can fare better against complications, so parental education on how to do this effectively should be a standard practice in all NICUs (Lv et al., 2019).

Empowerment

Another way to increase parents' psychomotor abilities is through an empowerment program. These help NICU parents to be more confident in their skills of caring for their child. Interventions such as the 4 phase COPE (Creating Opportunities for Parent Empowerment) educational empowerment program described and researched by Nieves, Clements-Hickman, and Davies can improve neonatal outcomes and decrease parental stress and anxiety (2021).

Another facet of parental empowerment is teaching parental self-care. This leads to decreased stress and anxiety as well as increased emotional stability which allows parents to better support their infant, leading to bettered cognitive and behavioral development of the neonate (Mosher, 2017). Parental empowerment programs can be combined with or added to parental education programs as Family Centered Care to further benefit the entire family unit. Even for parents who already have older children, the NICU may be a new and frightening experience and caring for NICU babies can be an entirely different experience than caring for a typical newborn. Therefore, all families can benefit from education and empowerment.

Basic Care

The next intervention is allowing parents/caretakers to complete the basic care of their hospitalized baby. This intervention is a step beyond parental education. It involves the parent actually caring for their baby as they would if their baby been discharged home after birth, rather than being admitted to the NICU. Basic care, described in the study “Family-Centered Care Improves Clinical Outcomes of Very-Low-Birth-Weight Infants: A Quasi-Experimental Study” includes, but is not limited to, diaper changes, bathing, swaddling, dressing, and minor healthcare procedures such as taking the baby’s temperature (Lv et al., 2019). According to Mosher, being involved in the basic care of the infant leads to less stress and anxiety (2017). Since Family Centered Basic Care benefits both the parents and the baby, it is an important addition to the checklist.

Basic Family Centered Care can also include involving caregivers in developmental care of the neonate, known as Family Centered Developmental Care (FCDC). According to “Recommendations for involving the family in developmental care of the NICU baby,” educating parents on the basic developmental needs of their NICU baby can better the child’s neurobehavioral scores after discharge (Craig et al., 2015). Developmental care should be included in parental education as it leads to improved outcomes. For this reason, FCDC is included in the Family Centered Care checklist.

Breastfeeding

The next evidence-based intervention included is breastfeeding. According to the American Academy of Pediatrics’ Section on Breastfeeding, breastfeeding is the best and healthiest option for the nutrition of infants and if that is not possible, then pumped or donated human milk is the next best option (Eidelman et al., 2012). According to

Eidelman et al., human milk leads to less complications in NICU patients, including decreased rates of sepsis and necrotizing enterocolitis because antibodies in the breastmilk speed up the development of the infant's immune system and make them less susceptible to infections (2012). Reception of human milk in the NICU also leads to lower readmission rates within the first year of discharge, lower mortality rates due to complications, lower rates of long-term growth failure, and less incidence of neurodevelopmental disabilities (Eidelman et al., 2012). Toddlers who received human milk when they were in the NICU are found to have higher intelligence scores, increased volume of brain matter, and greater mental, motor, and behavioral capabilities than those who did not receive human milk (Eidelman et al., 2012).

Breastfeeding also allows the birthing parent to physically bond with their child. According to Naylor and Clarke-Sather, parents are more likely to feel driven to breastfeed if their child is born preterm or in the NICU for other complications because they are educated on the importance of human milk and parent-infant attachment (2020). Whether the caretakers are breastfeeding or feeding their child human milk or formula through a bottle, this is considered Family Centered Care because the parents are involved in a process that is helping their child grow and develop. However, since breastfeeding is the preferred method, that is what will be included in the FCC checklist. Breastfeeding improves neonatal outcomes and, when it is involved in FCC, it helps parents adjust and decrease their stress and anxiety which is why it is an important addition to the checklist.

Private Rooms

The next intervention on the checklist is the utilization of private/single family rooms. In addition to extra privacy, single-family rooms allow for greater incidence of FCC. According to “Parent-Infant Closeness, Parents’ Participation, and Nursing Support in Single-Family Room and Open Bay NICUs,” parents in the intervention group reported that they were able to perform more basic care to their infant, create better bonds, and both mothers and fathers were present more often when their infant was in a private room (Tandberg, et al, 2018). Additionally, nurses in the same study reported greater incidence of parent-infant attachment, more participation in care as well as medical rounds, and nurses said that they were able to provide families with more support when they were in private rooms without having to worry about privacy violations (Tandberg, et al, 2018). Some NICUs with private rooms even offer beds for parents to sleep in so that they can stay with their baby around the clock and provide overnight care. Single family/private rooms foster decreased parental stress and anxiety which leads to improved neonatal outcomes, so it is a beneficial intervention to be added to the FCC checklist.

Bonding

The next intervention can be called many names. These may include holding, infant bonding, skin-to-skin, or kangaroo care. All of these involve physical contact between the parent and the infant. Skin-to-skin contact is one of the most widely used FCC interventions. The study “When can I hold my baby? An audit of the time to first cuddle for preterm babies (<32 weeks) pre-introduction and post-introduction of a Family-Integrated Care model,” the first thing most parents want to do when visiting their child in the NICU for the first time is hold their child (Murdoch et al., 2021). The results

of this study also show that the closer to the time of delivery that a preterm baby is held, the better outcomes the child may have, such as decreased length of stay, and decreased time to the infant's first full feeding (Murdoch et al., 2021). This study also shows that NICUs that implement FCC have parents who hold their child sooner than the parents of children in NICUs without FCC (Murdoch et al., 2021). Skin-to-skin contact also has neurochemical benefits. Studies show that NICUs that utilize FCC and allow for skin-to-skin contact promote oxytocin release in preterm infants (Vittner et al., 2019). Oxytocin is a hormone that allows new mothers and their infants to learn each other's scents and promote parent-infant attachment as well as facilitates breastfeeding (Vittner et al., 2019). Skin-to-skin contact is an important facet of FCC and is on the checklist because it allows for other important parts of FCC to be present.

Bonding between parents and their neonates is important for many reasons. One of these is prevention from harm. NICU patients who have not bonded with their caregivers are at increased risk for pediatric abusive head trauma (PAHT) (Allen, 2014). PAHT, sometimes known as Shaken Baby Syndrome, is any type of intentional head trauma that results from blunt force head injury and/or shaking (Allen, 2014). Another risk factor for PAHT is inconsolable crying which is common in NICU patients diagnosed with Neonatal Abstinence Syndrome (NAS) when they are withdrawing from illicit substances (Allen, 2014). When FCC is implemented and caregivers create attachments with their baby in the NICU, it acts as a prevention strategy and the baby will be at lower risk of harm from PAHT when they are discharged.

Technology

The final intervention for the checklist is the implementation of FCC technology to the NICU. One such example of technology is the use of cameras over the patient cribs in the NICU that allows parents to view their child at any time, even when they are not able to be physically present in the hospital. This FCC intervention is becoming more common, however, there is limited information into the effect of these cameras, but Gibson and Kilcullen performed a systematic review of what research does exist in “The Impact of Web-Cameras on Parent-Infant Attachment in the Neonatal Intensive Care Unit” (2020). This study indicates that positive effects of the cameras allow for parents to feel closer to their child, increased responsiveness (especially to conversations over the phone with nursing staff), and decreased stress and anxiety (Gibson & Kilcullen, 2020). More research still needs to be done on this intervention, however, since it is known that FCC interventions that decrease parental stress and anxiety can also positively affect neonatal outcomes, and these web-cameras have the potential to be further improved, the use of FCC technology should be added to the checklist along with the orientation of caregivers to this technology so that it can be used to the best of its ability and benefit the whole family.

Feasibility and Sustainability

Any implementation of a new protocol can be a potentially expensive and daunting change that may cause hesitancy among hospital staff. Family Centered Care has been shown to be a benefit to NICU patients and their parents (O’Brien et al., 2020; Nieves et al., 2021; Heo & Oh, 2019; Lv et al., 2019; & Yu et al., 2017). FCC is highly feasible in Neonatal Intensive Care Units as they typically already have access to many aspects of FCC, such as breastmilk/breastfeeding and the ability to allow parents to

participate in care. Whether or not it is sustainable is partially reliant on whether or not parents actually participate in the program. It is likely that parent participation in FCC programs would be high as evidenced by previous studies, including one conducted by Maria et al., which found that parental engagement in the NICU was high and especially higher among NICUs with FCC programs as opposed to those without (2021). Other studies have shown similar results which indicate that sustainability of FCC in any NICU would be high.

Another factor that affects the sustainability of FCC is the willingness of leadership to allow these changes. Since implementing an FCC checklist is a relatively inexpensive change that benefits such a vulnerable patient population and staff, the potential of this willingness is likely high. Other stakeholders also play a role in the sustainability of FCC in the NICU. In health care, stakeholders include patients, families, staff (nurses, physicians, et cetera), and higher leadership. In order to be sustainable, the interventions must be relevant to these stakeholders. The FCC checklist is very relevant to all of these stakeholders because it is positively impacting the health and wellbeing of premature and/or critically ill infants in the NICU (Quinn & Menon, 2020). The FCC checklist must also align with the institution's mission and values, but these are typically related to ensuring quality of patient care, which is the intended use of the FCC checklist.

Most hospitals with Neonatal Intensive Care Units already have much of the capabilities to implement many of the Family Centered Care interventions on the checklist. Parent-provider education is already used in all clinical settings, the only potential change that would need to be made would be some staff education on providing

therapeutic communication, but this is a concept that is taught in nursing and medical schools, so it would likely be an unnecessary change (Arnold & Boggs, 2020).

There are many existing education and empowerment programs available for hospitals to adopt. These include the COPE NICU Program, the Empower Program, the Parent Education Empowerment Program, and others. Many of them utilize education that NICU staff already know how to teach parents about. There may be some cost involved in gaining the rights and access to these programs, but the benefits of educated and empowered parents of NICU patients far outweigh any cost involved. For programs in which nurses conduct the teaching, there would only be a one-time cost of training the nurses and then trainings can easily be completed with each NICU family. Basic care of NICU babies is a skill that all NICU nurses already possess. Teaching parents would be easy to complete any time the families are present and staff can take the opportunity to allow the caregivers to help.

Breastfeeding is something that NICU parents are already shown to be motivated to do when educated on the importance, which could also be included in the NICU orientation teaching and parents can make that decision to breastfeed early on (Naylor & Clarke-Sather, 2020). Many NICUs also have access to donor breastmilk for families or caregivers unable to supply their own. Kangaroo care/skin-to-skin contact is one of the best ways to promote parent-infant attachment and is also extremely cost effective. All it requires is for the parent to be present to hold the baby and a nurse to assist the parent in picking up the baby. Some nurses may not have experience with lactation assistance and would require additional training in order to do this, or one lactation consultant could be available on the unit and make rounds to each family to assist.

The switch to single-family rooms for NICUs that do not already utilize them would be one of the more expensive and difficult undertakings for NICUs to implement the Family Centered Care Checklist. However, as more evidence becomes available on the importance of single-family NICU rooms, the more it is recommended to be a standard of care, so most NICUs will get to the point where it will be necessary to make this transition regardless of the cost. Milford, et al, documented the transition process of the Magee-Womens Hospital of the University of Pittsburgh from a ward design to an individual room design about 15 years ago (2008). This unit sees about 1,900 patients each year and utilizes many aspects of FCC to be an extremely successful NICU. They are one of many success stories that prove the efficacy and necessity of private NICU rooms.

Technology is likely the other intervention that would be costly. However, utilization of technology does not have to be that expensive. Some NICUs, rather than using cameras for 24/7 livestreaming of the infant, will have nurses and other NICU staff conduct daily Facetime or Skype calls with parents who are unable to be present in person in order to provide updates and allow the families to see their hospitalized infants and have some degree of bonding (Gingell Epstein et al., 2015). While this is not as ideal as fulltime livestreams, which is also not as ideal as parents being able to be present in person, it is however more cost-effective than the livestreams and allows for communication with staff in addition to seeing the baby and is more interactive than a simple phone call.

Each intervention on the Family Centered Care Checklist for the Neonatal Intensive Care Unit is feasible, sustainable, and an evidence-based necessity for the well-

being of NICU patients and their families. There may be some cost involved, but the proven benefits of FCC for holistic NICU care far outweigh the material costs of any changes.

Conclusion

Neonatal Intensive Care Units care for an extremely vulnerable population of hospitalized patients. Neonates are newborn babies and are admitted to intensive care when they are born prematurely and/or are critically ill. The rate of preterm birth is relatively high in the US and many newborn infants spend time in a NICU. Complications may arise during the infant's stay in the NICU including infections, respiratory issues, brain bleeds, and more. NICU patients often require many medications, machines, nurses, and doctors to keep them alive. While this time in the hospital is stressful on the neonate's body, it is also detrimental to the emotional and mental wellbeing of their caregivers.

Research shows that Family Centered Care is beneficial to neonatal outcomes (such as decreasing the rate of complications) and their caregivers (decreasing stress and anxiety). There are many interventions that can be used in NICUs to implement FCC and create these benefits. However, there is no standard way for NICUs to incorporate all of these interventions.

This thesis utilized a review of literature to determine the most beneficial evidence-based FCC interventions that can be used in the NICU. These interventions were organized into a standard checklist, and the interventions on it include communication, parent education, education, basic care, breastfeeding, private rooms,

bonding, and technology. This checklist (see Appendix A) can be used by nurses and parents in the NICU to ensure quality of care and benefit families.

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Appendix A

Family Centered Care Checklist

Communication

- Parents spoke with staff today
- Questions answered appropriately
- Communication was therapeutic and effective

Parent Education

- Parents were instructed on what to expect in the NICU upon admission
- Follow-up evaluation conducted and questions answered

Empowerment

- Parents participated in an empowerment program upon admission
- Follow-up evaluation conducted and questions answered

Basic Care

- Parents participated in at least one basic care session today
- Parents performed the following skills (circle all that apply): diapering, feeding, swaddling, bathing, medication administration, other: _____

Breastfeeding

- Baby received breastmilk today
 - Via: tube feeding, bottle, breast (circle one)
 - From: birthing parent, donor/milk bank (circle one)

Private Rooms

- Unit has private rooms available
- Parents have utilized space available in the room to store personal items

Bonding

- Baby was held skin-to-skin for at least 1 hour today by a parent

 Technology

- Room is equipped with a web camera
- Caregivers have been oriented to technology in the room
- If parents are not present in person today – parents have checked in via the livestream today