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Winter, M. (2020). Family-Centered Care in the Neonatal Intensive Care Unit. *The Eleanor Mann School of Nursing Undergraduate Honors Theses* Retrieved from <https://scholarworks.uark.edu/nursuht/115>

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Family-Centered Care in the Neonatal Intensive Care Unit

An honors internship submitted in partial fulfillment of the requirements of the degree of
Bachelor of Science in Nursing

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May 1, 2020

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Introduction

“Family-centered care is a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients” (Jolley & Shields, 2009). Principles guiding family-centered care include “information sharing, respecting and honoring differences, partnership and collaboration, negotiation, and care in context of family and community” (Kuo et al., 2012). This is a well-known concept, but unfortunately isn’t practiced as much as it should be considering the positive outcomes it can provide.

Family-centered care can be useful in any clinical scenario, but more so in the Neonatal Intensive Care Unit (NICU). Having a preterm infant admitted into the NICU is not an ideal situation, and can cause high levels of apprehension for the parents. “Stress experienced by parents whose infant is hospitalized in the NICU is strongly correlated with anxiety, fatigue, depression, and sleep disruption” (Busse et al., 2013). These angst feelings fluctuate depending on if this was an expected outcome, the condition of the infant, and the length of their stay in the NICU. Alteration in the parenting role is the main source of stress. Parents find it difficult to carry out normal parenting activities in the critical care setting (Busse et al., 2013). Practices such as breastfeeding or holding the baby are typical experiences for parents of the newborn, but these actions are limited in the NICU. Seeing the infant’s fear or weakness during separation causes feelings of hopelessness and stress for parents (Collura & Wolfe, 2015). These feelings can continue and even worsen after discharge. The anxiety faced in the NICU is associated with parental acute stress disorder and post-traumatic stress disorder (PTSD), as well as negative developmental delays for the infant after discharge (Busse et al., 2013).

Understanding that time in the NICU puts both the parents and infant at risk for the future, I wanted to observe specific ways that family-centered care could be accomplished in this setting. The advantages of practicing family-centered care extend further than just in the immediate moment. I decided to focus my study in the NICU at Willow Creek Women's Hospital, the only hospital in Northwest Arkansas dedicated to women's health. I had the opportunity to spend many hours following nurses, therapists, managers, and educators to observe how this unit meets families' needs through their various multidisciplinary actions involving family-centered care.

Performance Evaluation

Completing this internship boosted my confidence in my nursing practice, but also showed me areas of self-improvement. I found my weaknesses were being deficient in knowledge regarding disease processes, medications, and interventions for NICU infants. The internship allowed me an opportunity to enhance my learning. Due to the lack of knowledge in these areas, I often found myself hesitant to participate in the education and emotional needs of these families. Another weakness I recognized was being able to put ethical beliefs aside when faced with difficult family situations. Although I would never verbally state my beliefs or alter the care I give, I find myself reflecting and evaluating both sides of the situation. I have been faced with multiple moral dilemmas throughout this internship. Some of these include situations involving opioid addiction, physical abuse, and anti-vaccination beliefs.

Some of the strengths I portrayed during this internship was always coming prepared with a positive attitude and being willing to learn at all times. Initially, I asked a lot of questions about Willow Creek's policies and various skills performed during care times. As the semester continued, I became more confident in my practice and felt that I could handle assessments and

feedings (further referred to as care times) on my own. I felt like my nurse could depend on me and was optimistic about my capabilities. There was one particular day that I was able to perform under pressure during a Cesarean section. Since this was a high-risk pregnancy and the fetus was under distress, I had to collaborate with the nurse and neonatologist to work diligently and efficiently to revive the infant and transport the neonate to the NICU. Another general strength I used is being personable and willing to initiate therapeutic relationships. I enjoyed being able to communicate with family members, nurses, therapists, and doctors.

Internship Evaluation

There were several benefits of this internship. The growth in my confidence and being comfortable in the NICU setting was the most helpful and irreplaceable part of this experience. The care time repetition every 3 hours increased my courage and determination. I came into the internship very nervous about working with infants that seemed so small and fragile, but now I feel capable performing the duties efficiently. I learned a lot about caring for NICU infants with varying diagnoses and complications. Being able to complete this internship was almost like an additional obstetrics (OB) clinical that was centered around the NICU. I am now more comfortable around NICU infants and their families. By observing a multitude of family dynamics, I am becoming a more well-rounded future nurse. I am able to view each situation in its entirety and find interventions that can be implemented while keeping the patient and family in the center of care. The longer the infant stayed in the hospital, the easier this became for me.

Having a higher acuity of patients could have improved this internship. A majority of the infants were feed to growers and did not require acute care. A barrier I faced during the internship was a sharp decline in census at the beginning of the year. Many nurses were asked to stay home due to the low census, and that was very difficult for me. It would have been better

having a more consistent patient population. Many nurses were unsure of my role, making them hesitant to ask me for help where I could have better assisted the team. However, the nurses I worked with were very knowledgeable and taught me more than I could have asked for. Overall, this internship prepped me for an easier transition from moderate acuity patients to more intense cases.

Connection to Previous Course Work and Classes

I luckily completed my OB class and clinical earlier in the semester, so when I started my internship at Willow Creek, I had a sufficient basis of knowledge in the unit. Through my time at Willow Creek, I came to realize just how much I had learned during lecture and experiences at clinicals. I spent two days in the NICU at Mercy Hospital in Rogers where my knowledge improved tremendously. Being able to complete my internship at Willow Creek was similar to a NICU-focused clinical. One of the first things we learned in class is the appearance of a preterm infant and assessments that are performed. When I first started in the NICU, I was not surprised that these infants were very skinny, had thin and transparent skin, and were very flexible with no muscle tone. During care times I practiced taking vital signs and was able to evaluate whether or not these values were within normal ranges and relate it to the patient's condition. We assessed the infant by listening to their heart, lungs, and bowel sounds as well as checking to make sure their skin was intact. At one point I was able to recognize the presence of a heart murmur. We utilized continuous positive airway pressure (CPAP) machines and suction equipment to improve the infant's respiratory rate and oxygen saturation. Each day we took the infant's weight and measured their urine output to determine their fluid status and if they were utilizing nutrients appropriately. It is important to promote healing and growth in the newborn, so our care times were scheduled every 3 hours to encourage rest and motor development while reducing stimuli.

In between care times, it was important to maintain the infant's body temperature with a neutral thermal environment since they are not able to regulate their own temperature.

I was able to recognize different pregnancy and delivery complications and relate them to the effects of the newborn. Some of the conditions I witnessed were meconium aspiration, hyperbilirubinemia, gestational diabetes, and pre-eclampsia. Some infants suffered from meconium aspiration during delivery, progressing to pulmonary hypertension. Once infants aspirate, they have an impaired surfactant production and use which leads to atelectasis. This further leads to impaired gas exchange and pulmonary vasoconstriction, and ultimately ends in pulmonary hypertension (Murray et al., 2019). Many of the preterm infants had to receive phototherapy due to a diagnosis of hyperbilirubinemia. This occurs when there is a buildup of bilirubin in the blood from the breakdown of red blood cells. It is the infant's liver's job to remove this bilirubin, but the process is hindered due to being immature. This causes the infant's skin to appear yellow, further described as jaundice. Phototherapy helps lower the bilirubin levels in the blood through a process called photo-oxidation (Murray et al., 2019).

A maternal complication that can be observed in preterm infants is gestational diabetes. If a mother has gestational diabetes, she is very hyperglycemic through the pregnancy, but the condition resolves shortly after delivery. In this case, the infant is hypoglycemic with glucose levels less than 60 mg/dL, and appears shaky, lethargic, apneic, and hypothermic (Murray et al., 2019). This was treated by administering fat emulsion with 20% intralipid to the infant in hopes their glucose level would increase while promoting growth through extra calories. A major complication I witnessed that caused a rapid response by the healthcare team was pre-eclampsia. This is characterized by high blood pressure in the mother. In this situation the mother was 30 weeks pregnant and her fetus was showing late decelerations. This indicated uteroplacental

insufficiency meaning the baby wasn't getting enough oxygen and required an emergency Caesarean section. I was able to assist the neonatology team once the infant was delivered and we successfully transported her to the NICU. We performed 1-minute and 5-minute APGAR scores and used tactile stimulation to help oxygenation. I was able to provide help and support to the team because of my background knowledge and experience.

From my previous course work I understood the various risk factors that could surround a NICU infant. The families who are considered high-risk have a greater chance of having a child that may need NICU care. Adolescent pregnancy is one of the circumstances commonly seen and needs special consideration from the nurse. Prenatal risks influence outcomes for both mother and newborn. It is important to assess support systems available for families with unmet needs to reduce risk for both the mother and infant. When facing these families, we taught topics such as nutrition, self-care, stress reduction, attachment to the infant, care of the infant, and breastfeeding techniques. It is also important to eliminate barriers to health care and provide referrals such as the Special Supplementation Nutrition Program for Women, Infants, and Children (WIC). "WIC provides federal grants to states for supplemental foods, health care referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and to infants and children up to age five who are found to be at nutritional risks" (U.S. Department of Agriculture). Another population we faced were families struggling with substance abuse. By remaining non-judgmental, we were able to teach the parents about feeding, rest, and bonding when they were present at the facility. Learning about the different types of effects of various drugs helped me determine what type of withdrawal the infant was experiencing. Infants exposed to smoking during pregnancy appear shaky and unsettled, while

infants exposed to opioids during pregnancy have an inconsolable cry due to withdrawal after delivery (Murray et al., 2019).

During my OB clinical, I noted many things NICU parents can do to promote healing and growth in their infant, and I was able to further teach this information to the parents at Willow Creek. The healthcare team wanted parents to demonstrate bonding behaviors with their infant, verbalize understanding of their infant's condition, and show comfort and confidence when performing care for their infant. One of the easiest and most beneficial things for parents to practice is 'Kangaroo Care' or 'skin to skin contact'. This has been shown to promote growth, help with breastfeeding, and stabilize vital signs as well as improve mental status for the parents (Murray et al., 2019). We encouraged parents to practice this for at least one hour at a time and multiple times a day if possible. Another topic I was comfortable in teaching was the importance of breastfeeding and how breast milk contains appropriate nutrients and infection-preventing components. I was able to assist mothers with positioning, latching, sucking patterns, removal from breasts, and explaining the frequency and length of feedings. Having a person of support during that time, whether it was a family member or Willow Creek's lactation specialist, really increased their confidence to successfully breastfeed.

The prior education I was able to attain regarding processes in the NICU did enhance my time at Willow Creek. However, additional content and course work could have helped me succeed even further. Our OB class only lasted 8 weeks and was very broad. It covered content on pregnancy, labor, postpartum, and healthy and sick babies. Since there was so much material to cover, only a small portion was focused on NICU infants. Our simulation activity for the class involved caring for a mother in labor from admission to delivery. Her newborn was healthy and had no complications, so we were not able to practice taking care of a critical infant. Along with

additional lectures and content, a longer OB clinical rotation would be extremely advantageous. This clinical lasted 6 days, with 2 days spent in labor and delivery, 2 days spent in postpartum, and 2 days spent in NICU. Being able to participate in care and practice new hands-on skills is where I learn the most. If I had more time in the NICU I would have been even more prepared to excel during this internship.

Nursing Theories, Methods, and Knowledge

There are many theories, methods, and knowledge that guides the practice of nursing. The main model that applied to my time spent in the NICU is the Socioecological Model. This model views behavior changes at multiple levels including individual, interpersonal, organizational, community, and political (Yoder-Wise, 2015). Not only does this help nurses understand the reasoning for behavior changes, but it also requires nurses to look the situation in its entirety and could potentially make them more empathetic. Sometimes healthcare professionals are unaware of what families are facing at home, at their job, in their neighborhood, or even within their own being. Practicing the views of this model allowed me to be more considerate and open-minded when providing care. Another model commonly used is the Health Promotion Model. As a student and future nurse, I can empower people to make better choices through education, counseling, and continuous support (Yoder-Wise, 2015). By motivating and coaching parents throughout their stay in the NICU, I was able to help them gain confidence and see the benefits of different cares for their infants.

Personally, I tried to maintain personality hardiness to view each day and patient as a new learning opportunity. The NICU can be filled with stress, but I used courage and ambition to create opportunistic situations. I stayed committed to my patients and wanted to be actively involved in their care. When faced with adversity, I remained under control and perceived events

in a way that I could handle. I was challenged to view change as something that could help my personal growth and provide me with new opportunities. Practicing these ideas helped me learn from both positive and negative experiences and sharpened my resilience.

The main concern in nursing is maintaining patient safety. I was able to practice this by using the STAR (Stop, Think, Act, Review) approach. Since the NICU infants are so fragile, it is important to reflect on potential interventions whether that be medications, feedings, or respiratory therapy. Staying current with the best evidence and practices from credible sources helped me improve my practice. Additional important nursing actions include prioritization and time management. To be successful in the nursing world, it is imperative to be competent in these areas. Prioritizing systemic before local, acute before chronic, and actual before potential helped determine which patient needed to be seen first (Yoder-Wise, 2015). Staying organized, prepared, and avoiding procrastination helped with my time management skills. The nurse and I were never late when completing care times or administering medications. We clustered our care to get as much done at one time to be as efficacious as possible.

The most important factor in promoting family centered care is always providing a therapeutic relationship and communication. Elements of a therapeutic relationship for a nurse includes unconditional acceptance, genuineness, empathy, attending and listening, open-ended questions, and silence (Yoder-Wise, 2015). Therapeutic communication helps facilitate these interactions, assist with problem solving, examine behaviors and alternatives, and promote self-care and independence (Yoder-Wise, 2015). It is necessary to be this figure to NICU parents because many of them are very discouraged and scared, especially when it's time for discharge. I wanted to serve as a figure that parents could trust and someone they could express their concerns to. Not only does that help the well-being of the parents, but the nurse as well because

the shared relationship is on the same page and there is no miscommunication. There are some parents who have no interest in having a relationship with the healthcare providers or caring for their infant's needs. In these situations, I continued to support their needs and tried to exhibit dependability and consistency.

Relationship to Future Goals

When starting this internship, I did not have an idea of what area of nursing I wanted to practice upon graduation. Little did I know, I would be offered a position as a nurse in the NICU at one of the top hospitals in Arkansas. I will be able to use all the knowledge, practice, and skills I have learned during this internship and apply it to my future practice as a NICU nurse. I believe having the opportunity to complete this internship will make my transition from a student to a nurse much easier and more comfortable since I have an idea of the role of a NICU nurse. Not only do I have a perception of what my future position holds, I have gained invaluable experience working with other nurses, therapists, and doctors. I am much more confident in my practice and being able to effectively communicate with different members of the healthcare team. I have been able to view various family dynamics and learn different resources I can provide to them as a nurse. Watching the nurses at Willow Creek accommodate to families' needs has been very encouraging and inspires me to do the same for my future patients and their families.

My overall education and career goal is to obtain my Master's or Doctorate in Nursing Practice. As I am still unsure which specialty to pursue, I am very interested in Neonatology. During this internship I had multiple opportunities to talk and work with Willow Creek's Neonatal Nurse Practitioner. She provided great insight about her job responsibilities and gave me several pieces of advice. There are no schools in Arkansas that offer further schooling in

Neonatology, so if I wanted to continue my knowledge and practice in this area, I would need to look at online or out-of-state programs. Spending this time at Willow Creek is only a small steppingstone to accomplish my highest goals. For now, I will use this experience to strengthen myself as a Registered Nurse so I can become skilled and efficient in my unit. Once I feel proficient in my position, I then plan to look into continuing my education.

Learning Objectives

My main objective for this internship was to observe family-centered care in the NICU. This practice was examined in a variety of ways during my time at Willow Creek. The first thing I noticed was that Willow Creek offered different classes for parents who had an infant admitted to the NICU. These classes included an initial welcome class, discharge class, and three infant massage classes. After attending these classes, I was very impressed with the care and consideration shown to the parents. The instructors provided many teaching techniques to meet different learning styles. I observed verbal instruction, visual aids, and mainly hands-on and return demonstration approaches. Teaching was very thorough so that there were no misunderstandings. The instructors provided outside and community resources to refer to such as Smart 911, Infant Massage USA, and Arkansas Department of Health Infant Hearing Program. They also used evidence-based practice facts to support their teachings. One unique feature I found helpful is that the parents were provided with an infant CPR blow-up mannequin during the discharge session. They were able to practice with it during class and take it home along with information handouts and packets.

The patient's rooms at Willow Creek are equip with a pull-out couch for a parent to sleep on and a bathroom that includes a shower. Parents of NICU infants are provided with three meals per day during their stay. This is very convenient as most neonatal units do not offer this support

(Hookway, 2013). The nurses were practicable in their teachings related to family-centered care. I witnessed a lot of education regarding skin to skin contact and breastfeeding. The nurses always made sure the family was comfortable and understood what was said, even if there was a language barrier. They were quick to accommodate to individual family needs by changing care times based on availability, extending or shortening class times, or offering alternate implementations such as Skype or FaceTime so siblings could see their new baby brother or sister during flu season. The staff at Willow Creek collaborated with WIC and ARKids to cover and afford NICU infants' needs.

With many great practices observed, there are things that can be improved to better family-centered care. Starting with the classes offered, the area of teaching is very small making it uncomfortable and harder to promote conducive learning. Some of the classes were very lengthy which could potentially interfere with work, breastfeeding, outside appointments, and being present during rounds. I think some of these classes could be shortened and condensed so it is not such a big time commitment. At Willow Creek there used to be a NICU Support group on Thursday afternoons that allowed NICU parents to meet and discuss their feelings and current experiences in hope that they would find encouragement and peace within their situation. Unfortunately, this class isn't offered anymore due to the lack of a social worker. They are also in the process of cancelling the welcome class and letting the nurses teach it upon admission. This could be a burden on nurses who already have many tasks to complete, and the teaching might reflect this lack of time. Another drawback noted is that Willow Creek does not have an in-house translator and therefore the staff has to use a Blue Phone. The Blue Phone allows patients or families to speak to an interpreter via phone call in their primary language. The nurses will be the first to say how many limitations they face in this aspect and the need for an in-person

translator due to the high population of Marshallese and Hispanic families in Northwest Arkansas.

Interventions for Improvement

Even though there were many great implementations observed, I think it is important to reflect on areas of improvement and specific interventions for the future. Through my clinical rotation at Arkansas Children's Hospital and completed literature review, I have found some of the best family-centered care practices that Willow Creek could incorporate in their NICU. The application that I believe would fit best at Willow Creek is the use of a 'NICVIEW' that was observed at Children's. This is a camera system that is put in each infant's isolette and allows for continuous streaming of the newborn. Parents are given a log-in and password to view their infant at any time during the day from any location they might be at. Although this seems to be an expensive application, this would be a great attribute to promote family-centered care. Children's also provided a full-time in-house translator. Willow Creek could benefit from hiring a translator and using them as a resource rather than a Blue Phone to aid communication so parental stress could be decreased (Collura & Wolfe, 2015).

Willow Creek upholds a very friendly visitation policy for family and friends. I would encourage the hospital to continue to endorse this supportive policy as it is related to "positive responses for family first impressions, NICU environment, communication with the healthcare team, and relationship with the healthcare team" (Lee et al., 2014). Willow Creek allows for the family to be present during rounds and care times, however, some are not aware that they are welcome to be there and participate. "Families specify that rounds are better when a nurse is present, when the family is introduced and involved in the discussion, and when medical terminology is avoided or interpreted" (Kuo et al., 2012). It is the healthcare team's

responsibility to extend this invitation and encourage parental presence and participation during these times. A majority of parents claim that attending these sessions provide an increase in confidence as well as an ease in anxiety. “The benefits to parents of attending rounds, and the learning opportunities provided in family-centered care and communication should be emphasized for medical trainees and other healthcare providers working in neonatal intensive care units” (Grzyb et al., 2014). With this being said, the topic and suggestion of attending rounds should be expressed to parents when they aren’t overwhelmed during admission or transitioning to the unit. Members of the healthcare team should continually encourage parents on attendance and participation throughout their stay.

With the changes regarding social workers and educators who conduct the various classes Willow Creek offers, I think the families and staff could benefit from the implementation of a ‘Parent-to-Parent (PTP) Manager’ role. “A PTP manager can provide social activities for NICU parents to connect, share information, and support each other. A PTP manager can develop and arrange parent education sessions, including unit orientation and resource guides to empower parents while in the NICU” (Voos et al., 2015). With Willow Creek’s lack of a social worker and discontinuation of the welcome class, a PTP would be a great way to teach these classes and incorporate any other family-centered care activities that could be useful to the unit and the families while avoiding additional tasks for the bedside nurse.

Recommendation for Future Internships

After completing this internship, I would without a doubt recommend Willow Creek to any nurse who is passionate about the NICU or women’s health in general. Willow Creek is the only dedicated women’s hospital in Northwest Arkansas, which makes it unique to the area. While spending numerous hours in this facility, I came to conclude that all members of the staff

share one common goal, and that is to provide the best possible care for their patients. It is very obvious that each member of the healthcare team wants to do their individual part to improve the health status of their patient. The multidisciplinary approach used for each situation is very effective in making the NICU stay as convenient as possible. Nurses, nurse aides, therapists, doctors, and management all work together and maintain consistent communication to make sure patients are receiving the most diligent care to reach a desirable outcome. The morale of the unit remains positive, even during distress. For the unfavorable circumstances with difficult or uncooperative family members, Willow Creek's staff does everything in their power to make sure the infant is in good hands. They are always readily available to assist and arrange tasks to coordinate with the family and better infant care. If I were to have a newborn in the NICU, I would be very satisfied with the care I have observed at Willow Creek.

My main recommendation for this organization or future internships is that a legitimate internship program should be created. For my internship, there were not a lot of rules or guidance. This could sometimes be frustrating, as I am an avid rule follower. It was nice to be able to make my own decisions and go my own path, but I found myself facing a lot of gray area where I wished for more direction. I think it would be highly beneficial if the organization could create a schedule where the student spends time with multiple nurses as well as therapists or management. I think by providing an official internship, new graduate nursing students who participated would be likely to work there after graduating. Overall, I had a great experience at Willow Creek as I was welcomed by all staff members, I was continuously presented with learning opportunities each day, and most of all was able to grow in my practice as a future nurse.

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