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Family-Centered Care in the Neonatal Intensive Care Unit

Sarah Brown

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Sarah C. Brown

University of Arkansas College of Education and Health Professions

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Introduction

Family-centered care has not always been integrated with patient-care. In the mid-1900's, a movement began that altered the role of the family from observer to participant. With the help of family advocates, inclusive practices and partnerships between families, patients, and providers was initiated (Kuo et al, 2012). Now, family and patient-centered care is a widely practiced form of individualized care and relationship building between families, patients and their providers. Five principles shape the foundation for family-centered care. These include information sharing, respect and honoring differences, partnership and collaboration, negotiation, and care in the context of family and community (Kuo et al, 2012). Evidence shows that when these concepts are implemented, quality of care, patient outcomes, and patient satisfaction increase.

Family-centered care practices were designed for implementation in pediatric facilities of all kinds. The Neonatal Intensive Care Unit (NICU), is the ideal area for family-centered care to take place because of the unique and vulnerable nature of the mother/infant relationship. Neonates that are admitted to the Neonatal Intensive Care Unit face immense trials from their first day of life, while the parents experience serious physical, emotional and psychosocial challenges. These parents often report high levels of stress and increased incidence of depression (Feeley et al, 2020). The benefits of family-centered care are exceedingly important, especially for these populations and there is great gain in aiming to effectively implement such practices.

To gather relevant research on family-centered care practices, a search was conducted using the University library database resource. The CINAHL database advanced search was utilized. The terms ‘family-centered care’ and ‘NICU’ were searched with restrictions to full text articles published between 2015 to 2020. This search produced 68 publications. Results relating to family-centered care in the context of patient outcomes, the nurse’s role, cultural implications and barriers were included as part of this research. A search with the same terms and restrictions was conducted through PubMed and produced 72 results. Journals from both searches are included in this review. Other terms used in alternative searches were ‘culturally competent’ and ‘barriers.’

Objectives:

- Student will observe and analyze family-centered care policies in place at the facility compared with other NICU's family-centered care practices
- Student will research and observe family-centered care practices and their effect on patient outcomes, parent/family involvement and hospital readmission rates
- Student will observe the cultural implications surrounding patient and family-centered care such as cultural and language barriers and implement family-centered care practices accordingly
- Student will analyze and observe barriers and challenges to implementing family-centered care on the individual and institutional level
- Student will analyze the nurse's role in family-centered care as well as multidisciplinary involvement

Review of Literature

Although there is significant research still to be done, evidence has repeatedly shown the benefits of family-centered care practices in the NICU. One study conducted in China analyzed outcomes for neonates whose mother was involved in their care for four hours a day compared with mothers following the standard practice of the hospital, only seeing their infant over video call three times a week (Ly et al, 2019). The mothers involved in care were educated regarding infant development, hand hygiene, feeding methods, skin-to-skin contact and infection control as well as basic care practices such as changing, bathing, and taking the baby's temperature. Practicing family-centered care interventions demonstrated higher discharge weights in infants, increased rates of breastfeeding, shorter length of hospital stay and fewer days on nasal feeding or parenteral nutrition. A decrease was seen in readmission rates and complications such as necrotizing enterocolitis, retinopathy, and bronchopulmonary dysphagia for the group practicing family-centered interventions (Ly et al, 2019).

A study by Masstrup and others interviewed parents after their first experience of skin-to-skin with their premature neonate. The study found that skin-to-skin contact enhanced parental feelings of

closeness to their infant and they found it crucial in their bonding experience with their baby. This was true even for parents who were ambivalent or skeptical of skin-to-skin. Parents also reported they felt an increased sense of parental responsibility for their child and a desire to be involved in the care (Masstrup et al, 2018). Two reviews cited in this study found that "preterm infants' skin-to-skin contact with parents is associated with increased oxygen saturation, temperature, growth, breastfeeding and mother-infant attachment and lower mean respiratory rate and pain scores as well as risks of hypothermia, hypoglycemia, nosocomial infection/sepsis, hospital readmission and mortality (Masstrup et al, 2018)." Not only does skin-to-skin contact enhance parental involvement in care but it enhances premature infant outcomes.

Finally, a study analyzed the difference in several factors for mothers with infants in open ward NICUs versus small 6 pod rooms or single-family rooms (SFR) (Feeley et al, 2020). Mothers answered questionnaires related to stress levels, depressive symptoms, perceived support, family-centered care and sleep disturbances using evidence-based tools to rate responses. The study found mothers in the pods/SFR reported less overall stress and felt more welcomed and respected by staff. They were able to have ownership of their own space compared to mothers in open ward units that reported higher levels of stress related to a louder more chaotic environment. The mothers in open wards also reported feeling more restricted in their parental role due to limitations in space and privacy. Possibly the most significant finding was that mothers in the pods/SFR were present at the bedside an average of 84 hours the week before discharge compared with mothers in the open ward who were present for an average of 44 hours. This increase in parental presence is likely due to the ability of parents to room in, allowing mothers to be more involved in care around the clock such as bathing, feeding, changing and holding (Feeley et al, 2020). Family-centered care practices are important in involving and including parents in their infant's care while in the hospital, but it is also important to prepare parents to take on the full responsibility of caring for their baby upon discharge.

Despite the ample evidence in favor of implementing family-centered care, it is clear that not all facilities are implementing practices to the degree that they could. Several studies and articles identified

major and minor barriers to effectively implementing family-centered care. One article identified one barrier as a lack of understanding surrounding family-centered care from the provider and patient perspectives (Kuo et al, 2012). Parents often do not know what level of involvement in care is expected of them, and this creates difficulty if they are not engaged by staff or providers. Parents may also hesitate to get involved because of their fear of harming their small, fragile infants (Masstrup et al, 2018). Another study found that nurses sometimes struggle initially in their transition from the role of being the sole care provider to a facilitator of parent involvement in care (Toivonen et al, 2019). Lack of training and preparation for staff and providers expected to participate in and facilitate family-centered care was identified by nurses as a barrier to successful implementation. In addition, lack of buy-in or support from leadership and all disciplines, including doctors, made the execution more difficult (Toivonen et al, 2019). Nurses also identified time constraints, increased paperwork and increased workload as a barrier to achieving quality, family-centered care (Jakšová et al, 2016). Lack of financial support and reimbursement for implementing family-centered care practices was identified as a barrier in many studies (Gingell et al, 2015) & (Kuo et al, 2012). As identified previously, space plays an important part in allowing parents to feel at ease and welcome to participate in care. The absence of resources or ability to provide families with single rooms away from other patients has shown to be a barrier (Toivonen et al, 2019).

Language and culture barriers come with their own unique set of challenges. A study was conducted interviewing immigrant families about their experience with communication in the NICU (Patriksson et al, 2019). A common theme extracted from the interviews was the general lack of understanding between providers and families felt by the parents. Although the use of an interpreter enhanced communication, parents reported feeling that interpreters did not have adequate medical knowledge or terminology and frequently produced inappropriate answers to patient questions. This left the parents feeling lonely, misunderstood and worried or unsure about their child's condition (Patriksson et al, 2019). Another study conducted interviews with providers (nurses and physicians) to gain their perspective on the challenges and barriers of communication that come with caring for an immigrant

family. (Hendson et al, 2015). Providers reported the lack of basic communication makes it especially difficult to implement shared decision making and include families in NICU care practices. They too expressed the frustration that comes with difficult communication and lack of understanding between providers and parents. Providers emphasized the need to understand cultural norms and beliefs of individual families to be able to deliver better care (Hendson et al, 2015).

Nurses play an invaluable role in the implementation of family-centered care practices and helping to overcome barriers. Communication and organization are a couple of the key skills nurses must utilize in their practice. Strong communication allows nurses to be effective facilitators between physicians and families regarding the care and condition of patients. A nurse's ability to maintain organization impacts the level of individualized care and emotional support they can give to families (Jakšová et al, 2016). When parents struggle to adapt to their role as a parent or do not know how to be involved, nurses are the ones to provide direction and encouragement (Masstrup et al, 2018). Even in times when communication is difficult, such as in the presence of language barriers, nurses were still able to provide reassurance through non-verbal means (Patriksson et al, 2019). Nurses have a longstanding reputation for patient-advocacy. They have a role in protecting and advocating for patient and family rights regarding the family's level of involvement in the care of their infant (Jakšová et al, 2016). Nurses have established themselves as change agents and they remain crucial in the successful implementation of family-centered care practices.

While there are countless family-centered care interventions and initiatives that have been studied and validated, three studies seemed particularly helpful in providing specific intervention suggestions for the Willow Creek Women's Hospital NICU based on observations of current family-centered care practices and protocols. These studies will be expanded upon in the subsequent paragraphs. One study advocated for the inclusion of Music Therapists on the multidisciplinary care teams in the NICU (Standley et al, 2020). The article emphasizes the research and evidence behind improved outcomes for NICU patients that receive music therapy from specially trained music therapists following evidence-based protocol. Music therapists aim to systematically introduce differing levels of music, live or

recorded, to reduce overstimulation in infants and improve overall outcomes. Music therapists can also involve parents in care by teaching them appropriate strategies to avoid hyper-responsiveness allowing parents to bond with their infant (Standley et al, 2020).

A common practice implemented in many NICUs is the use of Facetime or Skype to include parents in the infant's care when they are unable to be present. Utilizing video as form of communication also enhances relationships and connections between providers and parents. A study that tested the feasibility of video updates found that parents rated their satisfaction with care received to be higher, in addition to increased satisfaction in their relationships with providers and sharing of information (Gingell et al, 2015). Despite limitations relating to access and availability of resources, such as internet or devices with video function, a family's use of video updates seems to be effective in inclusion of care and shared decision making when they are unable to be present. Implementation of a similar program in the local NICU may prove to be beneficial for families that must travel long distances or are required to be home with other children.

Finally, the implementation of a training program designed to equip providers to deliver effective family-centered care would be a positive intervention to encourage widespread implementation of family-centered practices. Nurses that participated in a related study reported that training and instruction received from mentor nurses with experience in family-centered care proved helpful in their ability to learn and implement the expected practices (Toivonen et al, 2019). This may serve as a solution to some of the recognized barriers to implementation such as role confusion and lack of understanding regarding family-centered practices.

Table 1: Literature Highlights

Author:	Aim:	Limitations:	Conclusions:
(Feeley et al, 2020)	The purpose of this study was to compare several factors such as NICU stress, perceptions of nurse-parent support, and family-centered care in mothers with neonates	The only limitation identified by the researchers was the fact that the mother participating in the study with the 6 patient pods were transferred to the single-family rooms midway through the study	The study found that mothers that stay in 6-patient pods and single-family rooms have lower levels of stress, report better family-centered care and demonstrate a greater number of hours per week present at the bedside.

	in open wards versus 6-patient pods and single-family rooms.	and they did not account for this change.	
(Gingell et al, 2015)	This study was conducted to determine the effectiveness of using Facetime or Skype to give parents updates regarding their infant's care and condition as well as foster meaningful relationships between parents and providers.	The limitations acknowledged by the researchers include the small sample size and homogenous nature of the group. The study may not be successful for individuals lacking access to resources for video conferencing or internet.	Overall, the study was deemed a positive way for providers to interact with parents of patient's. Parents indicated feeling that it was a helpful way to receive updates regarding their child's care and they reported increased satisfaction in their relationships with providers.
(Hendson et al, 2015)	The goal of this study was to examine the perspectives of healthcare providers when caring for new immigrant families in the NICU.	This study was conducted to gain healthcare provider's perspectives, meaning it gives a one-sided perspective. The sample group was taken based on a voluntary basis, therefore was not random. A final limitation is that the research was conducted only in metropolitan Canadian hospitals.	The conclusion of the interviews revealed that healthcare providers recognize barriers in caring for immigrant families related to language and communication barriers, including difficulty confirming understanding. Providers recognized the importance of understanding a patient's culture in delivering appropriate care and expressed interest in educational opportunities to enhance their knowledge base about their patients.
(Jakšová et al, 2016)	The aim of this study was to analyze the role that nurses play in encouraging family-centered care practices with patients and their parents.	The only limitation recognized by this study was that only studies published in English were included.	The study concluded that ill-defined roles for parents and nurses hinder implementation of FCC practices as well as time constraints and organizational demands. It also found that nurses are key players in communication and organization for parents and implementing family-centered care.
(Kuo et al, 2012)	The purpose of this paper is to outline the principles of family-centered care, highlight recent advancements as well as barriers in family centered care and propose steps for moving forward.	This paper slightly older than the other works which renders some of its information suggesting limited research of family-centered care invalid due to being out of date.	The article suggested barriers to implementing FCC practices might include general lack of understanding of FCC practices, little financial support for implementing such practices in addition to time constraints and the lack of research. Suggestions were made to improve FCC implementation such as further research, increasing awareness of FCC principles, or implementing bedside rounding.
(Ly et al, 2019)	The purpose of this study was to evaluate the impact of family-centered care practices on very low birth weight infants.	A limitation of this study is that the sample size was not measure because the data was simply assessed over a 12-month period. Infants were not randomly assigned to group, every other infant admitted was assigned to either the control or experimental group. No parent outcome measures were conducted.	The study found that in the patients with FCC interventions the discharge weights were significantly higher as well as breastfeeding rate. Length of stay was shorter and days of TPN or nasal feeding were fewer. Barriers were identified as not enough space and lack of training in staff. Parental presence is shown to improve breastfeeding and enhance positive feeding practices in neonates.
(Masstrup et al, 2018)	The purpose of this study was to examine the experience of parents immediately after skin-to-skin contact.	Parents that were deemed extremely vulnerable were excluded from the study which might have excluded different experiences. The study was only conducted on immediate experiences of skin-to-skin no long-	Results revealed that parents, even ones that were ambivalent about skin-to-skin contact initially, felt that skin-to-skin contact was extremely important in bonding with their infant and promoting feelings of closeness and relationship.

		term factors were assessed. Finally, data was written from interviewer notes which might hinder details from being transferred.	Parents also reported feeling a much stronger parental responsibility toward their infant and more interest in being involved in care. The study also showed how nurses play a critical role in the encouragement and promotion of skin-to-skin with parents and infants.
(Patriksson et al, 2019)	The aim of this study was to gain perspective from immigrant families about their experience in the NICU communicating with providers in the presence of language barriers.	A limitation recognized in this study is that only Arabic speaking families were included in the study and participation was on a voluntary basis.	This study concluded that overall parents identified 4 themes relating to their experience in the NICU. They included the parents felt accepted, encountered emotional warmth, encountered a lack of understanding and compensated for inadequate language skills. The results indicated that even with the use of an interpreter parents often felt misunderstood and lonely. Parents reported relying heavily on non-verbal communication from providers to feel reassured and safe.
(Standley et al, 2020)	The purpose of this article was to highlight the evidence for the inclusion of specially trained NICU music therapists in the interdisciplinary care team for premature newborns.	No limitations were identified by the authors of this article.	Music therapists aim to systematically introduce differing levels of music, live or recorded, to reduce overstimulation in infants and improve short term and long-term outcomes. Music therapists can also involve parents in care which enhances family-centered care by allowing parents to bond with their infant and teaches them appropriate strategies to avoid hyper-responsiveness.
(Toivonen et al, 2019)	The goal of this study was to understand the barriers and facilitating factors to implementing a training program in the NICU to prepare staff to implement family-centered practices.	Patient and family experiences were not recorded in this study, only nurses and manager's feedback. Doctors from every NICU were not included in this study.	Overall, the implementation of the program was effective. Nurse's reported it was challenges such as adjusting to a new role and implementing the program without full support and buy in from all disciplines. Most nurses reported the most effective aspect of the training program was the effective instruction and training given by mentor nurses to aid in learning the new practices before implementation.

Reflection:

My internship experience in the Willow Creek Women's Hospital NICU was comparable to an enhanced clinical experience. Each day I was present for the "huddle" with the oncoming staff and was paired with a day shift nurse by the charge nurse. Toward the beginning, I was paired with a new nurse each day. This was helpful because I was able to see how each nurse had their own methods of completing their responsibilities such as charting, preparing milk and engaging with families and it

allowed me to see how they maintained organization and efficiency. This also proved to be a challenge because I was rarely with the same nurse, which meant that each shift came with explanations about why I was there and what skills and responsibilities I was capable of. This usually meant that participation in the first care times were not encouraged, as I had not earned the nurse's trust yet.

After the first couple weeks, I began consistently being paired with the same nurse, Josey. At first this was a challenging relationship. It was obvious that Josey was wary of students. I had to consistently ask questions and offer my help to demonstrate my interest in participating in the patient's care and learning from her to fully gain her trust. After a couple shifts, I could tell I had begun to gain her trust because she allowed me to have more responsibility with the infants and was more compassionate toward me. Soon I was assisting with vital signs, assessments and care of all our patients. I began assuming total responsibility for one baby each shift. This was incredibly beneficial, as it allowed me to grow in autonomy and prioritization of care. I would receive report with Josey, from my patient's night shift nurse and perform the majority of care for that baby throughout the day. This included taking vital signs, changing the baby, setting up their feeding, holding them and anything else within my scope as a student. With supervision, I charted on the baby I was responsible for after each care time. I also had the opportunity to engage with parents when they were present and give them information and updates about their baby's progress and any changes. I was able to encourage and include them in the care I was giving and teach or demonstrate for them when they needed assistance. This allowed me to be a part of family-centered care.

One mother, whose baby I was caring for, was a first-time mother. It was such a joy and privilege to be able to observe them spending their first real moments with their baby. I felt even more honored to be able to inform them on their baby's condition and show the mother the best way to hold her baby to try breast feeding the first time. Being able to assume total responsibility for a patient really enhanced my learning experience and gave me the ability to feel like a nurse rather than just the nursing student. I had to really understand the patient, be organized and confident. This was helpful in preparing me for my role coming in a few months.

Throughout my internship experience, I was able to observe and participate in family-centered care. In addition, I had many discussions with Josey regarding the practices and policies in place at Willow Creek starting with the NICU set up. The rooms in the outer area of the NICU are all single rooms with a couch that expands into a bed and a shared bathroom between each room. This allows parents the ability to room in with their baby and be present as frequently as possible to assist with care, which parents frequently did. Babies that are very preterm and require intubation, IV intervention or other serious treatments are frequently kept in the inner core. This is one large area containing about 10 patient beds. This does not allow for much privacy or space for families besides a chair at the bedsides, and curtains that can be pulled around the area. As soon as an infant is well enough to be cared for in the outer core, they are moved to a single room which is more accommodating for families. The NICU policy of bedside report and rounding seeks to update and include parents when they are present as well as allow them to ask questions or voice concerns. Parents are informed of the feeding and care times for their babies so they can be present to participate in these when possible. Families also have the ability to call the NICU directly and speak with the nurse to receive an update on their baby as long as they have the appropriate identification number. Parents often did this in the morning and informed the nurse when they would be present during the day. Upon admission to the NICU, parents are expected to attend an informational meeting about their stay in the NICU, what to expect and what it means for their baby. Near discharge, parents are required to attend another class with important information about caring for their baby at home. Because this hospital is considered "baby-friendly," breast feeding is highly encouraged, and lactation consulting is available to patients that desire it. Skin-to-skin contact is also highly encouraged by staff for parents that desire this experience.

I was also able to discuss Josey's firsthand experience with practicing family-centered care. She told me a story explaining the difficulty of delivering effective family-centered care in the presence of language barriers. The patient she was caring for earlier that day before discharge had a Down's Syndrome diagnosis. The mother was a Hispanic woman that did not understand much English. Josey explained that she had used the 'blue phones' to go in depth and explain to the mother what Down's

syndrome is, including what it means that it is a genetic defect. She explained the difficulties that her child might have physically and mentally as she grows up. Josey explained that although this conversation took a significant amount of time, it is our job to advocate for the patients and families, especially while they are in our care. This mother may not get very much help or comprehensive education about her baby's condition besides her appointment with the Primary Care Provider after discharge. It is easy to fall through the cracks especially for a mother whose primary language is not English. This situation is especially challenging because even after this lengthy conversation using an interpreter with the 'blue phones,' it's hard to know how much understanding actually took place in the conversation.

One of my favorite aspects of the internship was getting to follow other disciplines, such as speech or occupational therapy, into their sessions with the patients. I learned a great deal from the therapists about their methodology and the reasoning behind their practices and the therapy they do. I got to observe baby massages for the first time and learned that it helps with neurodevelopment as well as digestion, which are big concerns for premature babies. From the speech therapists, I learned about the setbacks that premature babies encounter related to feeding practices. I was also educated on proper feeding techniques for premature babies and how to know when a baby is ready to advance. I observed breastfeeding education between mothers and lactation consultants and gained a great deal of knowledge about helpful positioning, techniques and ways to encourage and coach mothers.

Conclusion:

Although there are many effective family-centered care practices in place at Willow Creek there is still more that can be done to enhance the partnership between providers and families to result in improvements in both outcomes and communication. As previously mentioned, the implementation of a Facetime or Skype program would increase information sharing and parental involvement in decision making as well as strengthen relationships between providers and parents. Instituting a program like this would allow phone call updates from parents to be taken to the next level. Another effective intervention

to be considered is the inclusion of certified music therapists on the care delivery team at Willow Creek. Although other therapists may occasionally include music in their therapy sessions, specific intentional music therapy may prove to be an effective intervention to further improve outcomes in premature neonates. This type of therapy can be taught to parents and used as another avenue to connect them with their child and include them in care. Another suggestion to improve standardization and implementation of family-centered care practices specific to the NICU would be to hold staff training and education surrounding family-centered care in the form of sessions or individual mentoring. This could improve provider understanding of expectations and instill confidence in nurses experiencing role confusion.

I feel I had a very well-rounded experience in my internship. I have a better grasp on what it looks like to be a nurse in the NICU and implement comprehensive family-centered care. Although I am not going on to work in the NICU, I know the time I spent with patients performing skills, charting, practicing effective organization and communication, engaging in multidisciplinary discussions and learning the role of a nurse will serve me well in my profession. The research and observations I have completed relating to family-centered care have given me a greater understanding of the importance. I am more alert to the opportunities to engage families as partners of care and increasingly see the tangible value of doing so. I am confident that what I have learned will serve me well moving forward.

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