Neonatal Nurses' Perception of Family-Centered Care in the Neonatal Intensive Care Unit

Teresa Parry, RN, BSN, Bethany Fransen, RN, BAN, Maegan Nelson, RN, BSN

Creighton University

Abstract

Family involvement is an important part of care for the infant within the neonatal intensive care unit (NICU). Neonatal nurses recognize the importance of family-centered care (FCC), but need further education in this area to fully implement this practice. The purpose of this project was to investigate the perceptions of nurses regarding the implementation of FCC in the NICU through a descriptive survey. The research study performed was a descriptive non-experimental study using a survey administered to the nursing staff of two NICUs in the upper Midwest United States. The sample size was 30 (16.8%). In the smaller NICU, 23 surveys were distributed and 11 were returned (47.8%) and in the larger NICU 155 surveys were distributed and 19 were returned (12.3%). The measurement tool used was a FCC survey developed by the researchers. The survey was comprised of open-ended questions and question based on a Likert scale of 1-5. The mean experience of sample nurses in the NICU was 1.2 years. The nursing staff believed that FCC is beneficial to the patients (mean 4.6). In addition, the nursing staff believed that more education was necessary on the topic of FCC (mean 4.0). Finally, only 40% of the staff had the ability to write the unit mission statement. FCC is important in the NICU to improve outcomes and parent satisfaction. Four recommendations were discussed in this paper: 1) a unit specific guideline for FCC to reflect their needs and culture, 2) individual unit needs assessments to identify the knowledge base of NICU nurses on FCC, 3) education on the mission statement of the facility with correlation to improved outcomes and patient satisfaction, and finally, 4) further studies on unit layout effects on FCC implementation.

Neonatal Nurses' Perception of Family-Centered Care in the Neonatal Intensive Care Unit

Preterm birth cost the United States health care system more than $26 billion each year affecting almost 500,000 babies or 1 of every 9 babies born in the U.S. (Center of Disease Control and Prevention, 2013). The mortality rates in the United States of very low birth weight infants (< 1.5kg) and extremely ill infants have decreased largely due to advanced technology, new medications and a deeper knowledge of physiology. This advancement of treatment of NICU infants leads to more infants surviving and families enduring lengthy hospitalizations before infants can be discharged home. Admission of a newborn to the NICU is often a frightening, stressful and an emotional experience for the parents (Carter, Mulder, Bartram, & Darlow, 2005). Parenting a NICU infant places additional stressors on the new family unit. These stressors include: high-risk pregnancy recovery, uncertainty about the infant and the infant's possible survival or outcome, constant anxiety while the infant is in the NICU, and finally the transition of taking a complicated post-NICU infant home and providing care (Carter et al., 2005).

The recommended approach to health care for infants in the NICU is family-centered care (FCC). FCC is distinct in the belief that the best health outcomes can be achieved when the patients' family is actively involved in every aspect of care and provides emotional, physical and developmental support to the infant (Gooding, Blaine, Franck, Howse, & Berns, 2011). In the NICU, FCC means that the parents are the experts on their baby; the parents are not visitors, but an important part of the multidisciplinary team providing care to the infant. The concept of FCC has been discussed in the literature since the 1970's, but Harrison was the first to discuss the application of FCC in the neonatal population. Harrison (1993) discussed the basic principles of

family-centered neonatal care based on input from parents of NICU infants. Families identified principles they felt were of utmost importance. These principles identified were: open and honest communication between providers, nurses and families regarding every aspect of the infant's care; families and providers working together to alleviate the infant's pain; creating a better environment for the development of the preterm infant; and inclusion of parents in developing unit policies that benefit the infant (Harrison, 1993).

Significance

The Vermont Oxford Network (VON) is a not-for-profit organization that began in the 1980s with its goal to improve the quality and safety of the care provided in NICUs through research, education, and quality improvement projects (Horbar, Soll, & Edwards, 2010). VON is a voluntary network of many NICUs across the world. Through this network, guidelines and standards have been developed through research and evidence-based best practices. In 2000, VON organized a large group of 34 NICUs and focus groups to identify the best practices for NICUs based on evidence and research. During this 2000 meeting 51 potentially better practices (PBP), including FCC, were recognized by supportive evidence, research, and outcomes. FCC was identified as a PBP area and recognized as a standard of care in the NICU (Horbar et al., 2003). FCC has been shown to enhance the overall quality of care provided in the NICU leading to parents who are less stressed and more confident in their role and an improved hospital experience (Cooper et al., 2007).

Problem

The NICU experience is stressful for parents. While FCC is the recommended model of nursing care in the NICU, many neonatal nurses do not fully practice FCC (Trajkovski, Schmied, Vickers, & Jackson, 2012).

Purpose

The purpose of this proposed project is to explore the discrepancy in the acceptance of FCC which is a standard of care and the lack of implementation of FCC practices by NICU nurses. This project seeks to identify the perceptions of neonatal nurses about the practice of FCC and opportunities to enhance FCC.

Review of Literature

A review of the current literature was performed to assess the current state of knowledge about the NICU experience from a parent's point of view, and the influence of family-centered care on the hospital experience.

NICU Experience

Spear, Leef, Epps & Locke (2002) found that 53% of the NICU parents studied showed high levels of depressive symptoms. This was researched in a study to investigate family stress, coping, perceptions of their infant, and alterations in mood due to the hospitalization of their critically ill newborn.

It has long been known that the NICU experience is stressful. In a study by Carter, Mulder, Bartram & Darlow (2005), the experiences of parents of infants who remained in the newborn nursery were compared with the experience of parents with infants in the NICU. The study used the hospital anxiety depression scale (HADS). The study showed that the parents of NICU infants had increased anxiety. The other important finding in this study was that the NICU experience can negatively impact the father as well as the mother.

Raines in 2013 further confirmed the previous findings. The Raines' study found that mothers of NICU infants experience a moderate amount of stress based on the Parental Stressor Scale: Infant Hospitalization (PSS:IH) while the infant is in the NICU. A moderate amount of

stress was noted especially in regards to the discharge of the infant. The greatest level of stress however was due to an altered parental role while the infant was in the NICU.

A study by Mackley, Locke, Spear, & Joseph in 2012 focused specifically on the stress and depression experienced by fathers of infants in the NICU. This study used the PSS:IH as well as the Center for Epidemiologic Studies-Depression Scale (CES-D) to assess the anxiety and depression felt by fathers of NICU infants. Mackley et al. (2012) confirmed that fathers feel negative mental health symptoms and that their parental role is altered while their infant is in the NICU. This study is significant because previous studies had focused on the mother of the infant and the stress and depression the mother experienced. Mackley et al. (2012) provided data that the father is experiencing stress and that the father may need assistance in transitioning to his parental role.

Family-Centered Care

FCC has been studied repeatedly and these studies have yielded varied findings. In 2006, Byers, Lowman, Francis, Kaigle, Lutz, Waddell, & Diaz, reported a trial of FCC resulted in the conclusions that preterm infants who were cared for using FCC had fewer behavioral stress cues, less resource utilization and less usage of narcotics and vasopressors. Byers et al. (2006) did not find any statistical differences in complication rates, parental perceptions of the NICU experience, or parental satisfaction.

Studies by Jones, Woodhouse, & Rowe, 2007; Ladak, Premji, Amanullah, Haque, Ajani, & Siddiqui, 2013; Kuo, Sisterhen, Sigrest, Bizao, Aitken, & Smith, 2012 have shown that communication between parents and providers is improved and communication is more effective with FCC. Contrary to Byers et al. (2006), the study by Jones et al. (2007) showed an increase in parental satisfaction and perceptions of the NICU experience. Guilaume, Michelin, et al. (2013)

found that fear of death and anxiety obstruct parents ability to connect with their child. Parents in Guilaume et al. (2013) underlined the importance of communication and explanation to combat the emotional challenges of being a parent of a premature infant.

Another study on FCC compared infant outcomes in an open-bay unit in which parents may be asked to leave their infant's beside with outcomes in a family care unit where the parents could stay 24 hours a day. This study found that length of stay was decreased in the family care unit, as well as a reduced risk of development of moderate-to-severe bronchopulmonary dysplasia. There was no statistical difference in the infant morbidity in this study (Ortenstrand et al., 2010).

Stevens, Helseth, Khan, Munson, & Reid, in 2011 conducted a study on parent satisfaction in relation to single family rooms within a NICU compared to an open-bay unit. Findings included that patient satisfaction scores increased when being cared for in a single family room because the environment was more conductive to FCC (Stevens et al., 2011). Although not all units can afford to build single family rooms, it is important to remember that implementing practices that are beneficial to FCC can help to increase parent satisfaction, thus increasing the likelihood of better outcomes for the infants.

In 2012, a study showed that mothers who were in units that provided unrestricted access to the parents were more confident in their skills to care for their premature infants. These units had mothers with more breastfeeding success and with more infants continuing to breastfed three months past discharge (Wataker, Meberg, & Nestaas, 2012).

Satisfaction

In a non-experimental validity study of 550 parents of NICU infants, Tsironi, Bovaretos, et al. (2012), define age, gender, education level, length of stay, and place of residence as

indicators of parent satisfaction. Women were found to be more satisfied than men, while younger parents reported higher satisfaction scores than older parents. Sloan, Rowe, et al (2008) found almost half of the fathers were satisfied with the support they received in the NICU. An exploratory descriptive study by Latour, Hazelzet, et al. (2010) of 259 parents, 84 NICU nurses, and 14 Neonatologists identified the satisfaction markers for each group. Professional staff prioritizes contact assignment, lockers for parents, interpreter when appropriate, and presenting information at the parent's level of understanding. In contrast, the parental markers underlined knowing the prognosis, assurance of best care provision, and questions answered by staff honestly. An integrative review by Butt, McGrath, et al. (2013) describes two overall areas of dissatisfaction in the NICU. These areas of dissatisfaction are reported by the parents as lack of communication and inconsistencies in practice between professionals.

Regarding the importance of the parent nurse relationship in FCC, two studies discussed this topic and found that closeness is important (Fegran & Helseth, 2012; Reis, Rempel, Scott, Brady-Fryer, & Van Aerde, 2010). Reis et al. (2010) emphasized the need for awareness of appropriate involvement because of the positive impact FCC can have on the parents' role evolution and independence in caring for their child. Information was found stating that the parents' relationship with the bedside nurse was the most significant factor affecting their satisfaction with their NICU experience, emphasizing the importance of the nurse to parent relationship in FCC.

Summary

It has been suggested that addressing the anxiety and stress experienced by parents of premature infants needs to be integrated into the plan of care of the NICU patient. The use of FCC in conjunction with a discharge planning process assists parents to prepare for a transition

home. In addition, the literature has shown that providing a FCC environment will help to increase parent satisfaction. The NICU has been shown to increase stress and anxiety for many parents. FCC is the new standard of care for caregivers and providers to help parents in their experience with an infant in the NICU.

Theoretical Framework

The middle range theory, which was used as a framework for this study was the modeling/role modeling theory (MRMT) of nursing. At the core of MRMT is the concept of holism. Holism means to integrate the physical, emotional, social and psychological health of a patient. In the theory of MRMT, the nurse attempts to understand the world from the point of view of the patient and uses this view to provide care to the patient (Koren & Papapmiditriou, 2013). The MRMT theory is applicable to neonatal nurses' in that if the nurses are able to use the theory of MRMT and understand how important the role of the parents are in the child's life, that the nurse will be more willing to implement FCC. MRMT emphasizes the importance of building a relationship with the patient, or parents, to facilitate FCC.

The application of the MRMT theory was applied to nurses assisting families with the care of their infants, as well as with nurses teaching other nurses. Both of these applications need to be addressed for FCC to be fully implemented in a unit. Balmer, Serwint, Ruzek, Ludwig, & Giardino, 2007 showed in a study dealing with how medical pediatric residents learn how to implement FCC, the major factor was modeling the behavior of the residents' preceptors. Through this modeling, the residents learned how to talk and how to think things through to reach the correct diagnosis. Balmer et al. (2007) found that role modeling is a deliberate teaching strategy that provides examples for communication and clinical decision making. This study could be applied in the education of new nurses' in the NICU. By having appropriate

preceptors, the less experienced nurses could model their behavior of implementing FCC, through communication and interaction with the family.

Methods

Design and Setting

The research design is a descriptive non-experimental study using a survey administered to the nursing staff of NICUs in the upper Midwest United States. The settings were two Level III NICUs. One is a smaller NICU with 12 beds located in North Dakota; the other NICU is located in South Dakota and is larger with 60 beds. The mailed survey was one page in length, titled Family-Centered Care Survey. The survey included a combination of questions about years of experience, strengths and weaknesses of FCC, a Likert scale to rate FCC use in the unit and suggestions to improve FCC in the unit.

Sample

The sample included neonatal nurses who practiced in the NICU. All NICU staff nurses were recruited to participate in the survey, including specialty shift coordinators. In the smaller NICU, 23 surveys were handed out and 11 were returned (47.8% return rate). In the larger unit, 155 surveys were handed out and 19 were returned (12.3% return rate). The overall sample size was 30 (16.8%).

Ethical Considerations

Expedited approval was obtained from the institutional review boards of both facilities and Creighton University. All information was kept confidential and submission of surveys was done anonymously. Two individuals reviewed the surveys for data collection and analysis. Groups of data were used for demographic information to assure that there would be no identification of respondents.

Measurement Tool

The survey consisted of questions with a Likert scale of 1-5, with 5 meaning a response of “all the time” and 1 meaning a response of “not at all”. There were open-ended questions such as “What is the NICU's philosophy and mission statement?” and “What three things would improve the family support program in our NICU?” The single demographic data collected on the survey about the respondents was years of experience specific to the NICU (Appendix A).

Data Collection Procedures

A paper survey was placed in the individual staff mailbox of all the Registered Nurse (RN) staff in both NICUs. There was a specific deadline for the survey to be returned. The surveys included an envelope to place and seal the survey for confidentiality. South Dakota (SD) had a designated drop box in the unit to place the completed surveys. North Dakota (ND) had a stamped, self-addressed manila envelope hanging on a wall in the unit. The surveys were collected by research personnel in SD and one designated administrative personnel in ND.

Data Analysis

All returned surveys were analyzed using IBM SPSS Statistics version 21 for Windows. A descriptive non-experimental analysis focusing on means, frequencies, ranges and percentages was conducted. A demographic question about years of experience was included in the survey.

Limitations

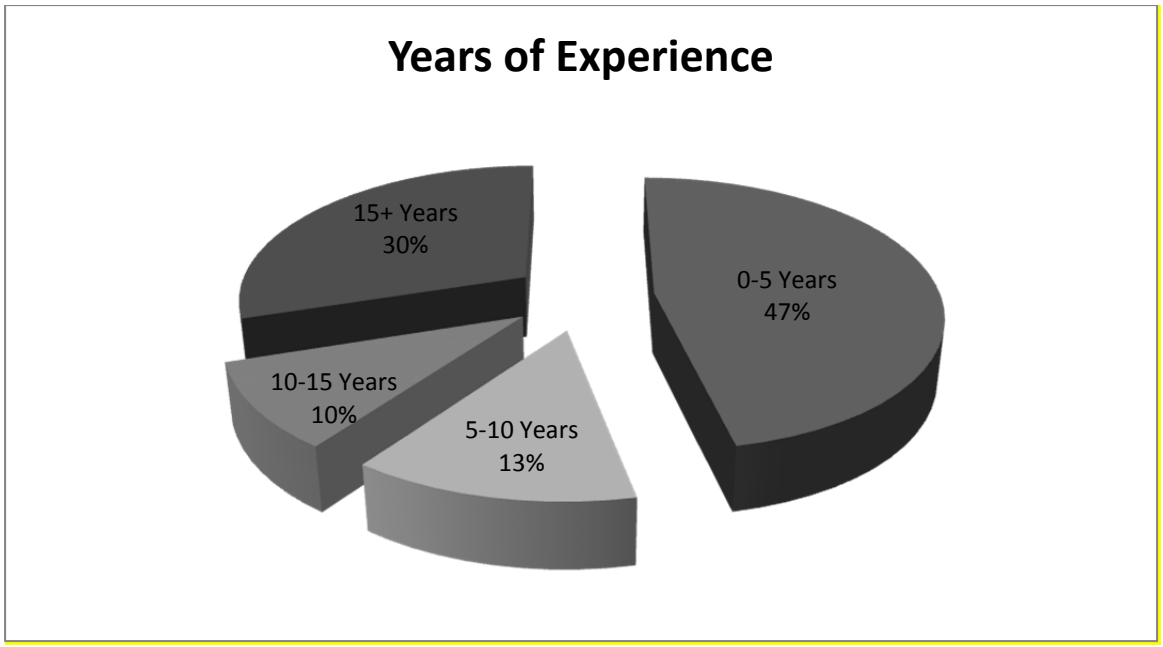
This study was small, applicable only to units in two states in the upper Midwest of the United States. The return rate of the survey was low at 16.8% of mailed surveys. Additional limitations to the survey included a lack of cause and effect, randomization, demographics of respondents, and a two week time limit for survey completion.

Results

The experience of the thirty RN respondents ranged from less than one year to 33 years' experience as a NICU nurse with a mean of 11.5 years and median of 6.5 years. Six questions were posed using a 1-5 Likert scale. Two questions scored a mean of 4.0 or greater; one question asked about the benefit of FCC in the NICU and the second question about the need for more education on FCC in the NICU. The lowest scoring question (mean 3.5) was on how receptive parents of NICU patients are to FCC. The second lowest question (mean 3.6) asked if the nurses are educated on proper use of FCC in the NICU. See Table 2 for a list of questions and their scores.

Table 1

Years of Experience



Three open ended questions were listed on the survey. The first question was, "What is the NICU's philosophy and mission statement?" This question was measured based on the ability of the responder to correctly write the NICU mission statement. Forty percent of the respondents correctly identified the mission statement. The respondents identified parental

involvement, single patient rooms, multidisciplinary involvement, and 24 hour visitation as strengths seen in the NICU (see Appendix B). Weaknesses mentioned by the respondents included lack of a unit guideline for FCC, inconsistent communication to families due to providers not always "on the same page", and in one unit the open-bay layout (see Appendix C). The larger unit respondents' suggested improving FCC through increased education, scripting, parental education through videos, rooming-in prior to discharge, increased continuity of provider care, systematic updating of parents by providers, and lower nurse to patient ratio. The smaller open-bay unit respondents' suggested improving FCC through unit remodel to private patient rooms, low nurse to patient ratio, include parents in weekly interdisciplinary rounding, NICU educator for staff and parents, and care conferences for long term patients (see Appendix D).

Table 2

Mean Scores of Survey Questions

QUESTIONS	Mean Score
Is family-centered care utilized within your NICU?	3.8
Are the nurses educated on proper use of family-centered care?	3.6
Are parents of the NICU patients receptive to family-centered care?	3.5
Does the interdisciplinary team contribute to the practice of family-centered care?	3.7
Is family-centered care beneficial to the care of patients in the NICU?	4.6
Do you feel that more education is necessary in the topic of family-centered care?	4.0

Discussion

The FCC approach is recognized by the VON and American Academy of Pediatrics (AAP) through the committee on hospital care, as improving patient outcomes and increasing satisfaction of NICU families. The sample size of the survey was small at 30. The respondents' median experience as a nurse in an NICU was 6.5 years with a mean of 11.5 years. The survey pointed out that there were major differences in the layout of the two units surveyed which was reflected in the topics discussed in the strengths and weaknesses. Due to these differences, any education program on FCC would need to be individualized to the unit based on layout. Suggestions to improve FCC in the NICU reflected the need to individualize to the unit. Both unit respondents stated their unit does not have a written guideline in the NICU for FCC.

A question on the Likert scale about if FCC is beneficial to the care of the NICU patient had the highest score at a mean of 4.6 and a median of 5. The respondents viewed FCC as beneficial to the NICU patient, yet suggestions from both units listed more education for both families and staff. A needs assessment on staff and families would be beneficial to explore the knowledge base of these NICU populations.

Less than half of the respondents were able to write the mission or philosophy statement for the NICU. More information is needed to address why the respondents are unable to write the mission statement of their facility. Additionally, one respondent suggested the mission statement be placed on the computer opening page used to complete electronic medical charting.

Respondents at the larger facility were most concerned with communication with the parents which led to many further suggestions. One suggestion made by a larger unit respondent was scripting. Scripting was suggested to improve a consistent message to the families, allowing staff to be more proactive and improving the continuity of care throughout the constant shift of

providers and bedside caregivers during the NICU stay. A short video on FCC for NICU parents is another suggestion to supply a consistent message, while establishing a baseline for NICU expectations.

A consistent theme by the respondents in the smaller unit was on adequate space and family involvement. A larger NICU with private rooms was suggested to improve bonding opportunities like Kangaroo care for parents, encourage parents to stay for longer periods of time at the patient bedside while decreasing the need to remove all family members from the NICU due to HIPPA concerns during a procedure or stabilization. A suggestion on family involvement by a respondent stated including families in the weekly interdisciplinary rounding. A guideline on FCC would be beneficial to identify staff roles and family participation in the plan of care promoting a proactive stance by nurses and families.

Conclusion

FCC is important in the NICU to improve outcomes and parent satisfaction. Neonatal nurses recognize the importance and benefits of FCC, but may require more education on the topic to become more proficient and confident in the important practice of FCC. Increased education on FCC would assist in the implementation of FCC in the NICU. A guideline for use of FCC in the NICU is recommended for each unit, to reflect their individual needs and culture. Further research is recommended to identify the knowledge base of NICU nurses on FCC.

Additionally, FCC unit guidelines should support the mission statement of the facility. The reason for 60% of the respondents' inability to write the mission statement of the facility should be explored. A needs assessment on orientation to facility and unit protocols is recommended. Facility education on the mission statement of the facility with correlation to improved outcomes and patient satisfaction is reasonable.

Lastly, every NICU is unique in its culture, location, layout, production, and mission statement. The open-ended responses in the survey from the respondents of two different unit layouts lead to differing viewpoints of FCC strengths and weaknesses. Further studies on open-bay vs. single bed units and its effect on the implementation of FCC are recommended.

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Appendix A

Family-Centered Care Survey

How many years of experience do you have working in a NICU? _____

Please answer the following questions using a 1-5 scale with 5 meaning a response of “all the time” and 1 meaning a response of “not at all”.

	“not at all”				“all the time”
Is family-centered care utilized within your NICU?	1	2	3	4	5
Are the nurses educated on proper use of family-centered care?	1	2	3	4	5
Are parents of the NICU patients receptive to family-centered care?	1	2	3	4	5
Does the interdisciplinary team contribute to the practice of family-centered care?	1	2	3	4	5
Is family-centered care beneficial to the care of patients in the NICU?	1	2	3	4	5
Do you feel that more education is necessary in the topic of family-centered care?	1	2	3	4	5

What is the NICU's philosophy and mission statement?

What are the current strengths and weaknesses of the practice of family-centered care within your NICU?

What three things would improve the family support program in your NICU?

Appendix B

Strengths

Unit in South Dakota	Unit in North Dakota
Parental involvement was encouraged at all levels	Weekly rounding
The Family Room is very useful	Staff encourages parental involvement, 24 hour visiting policy meaning parents can visit at any hour
There was an increased focus on FCC by the staff	Strong emphasis on breastfeeding, courtesy rooms available to breast pumping mothers; Staff is motivated to send infants home breastfeeding
Family participated in rounds and the doctors took time to discuss concerns with families	Small close-knit group of nurses who work well together
Private rooms was enjoyed by the families and makes kangaroo care very easy	Cards with pictures of infants and scrapbook pages given to parents
Excellent multidisciplinary team on the unit which regularly communicated with families	Family is important for the healing of the infant and is promoted
Parent support system and suggestions from parents on what we can do better in their infant’s care	More kangaroo care, especially for infants who are stable and doing well
Decrease nurse to patient ratio so that FCC can be better implemented	

Appendix C

Weaknesses

Unit in South Dakota	Unit in North Dakota
Different doctors and providers are not always "on the same page" so there is inconsistency of communication to families	HIPPA concerns with open unit, no privacy with this unit, difficult for parents to spend a long amount of time in the unit because little space
Nurses don't always follow the safety rules and avoid difficult families instead of engaging with them	When census increases, there is decreased ability to interact with families because of nurse/patient ratio
More education needs to be provided to families on FCC	Limited space and visitors at each bedside in small unit
Difficulty getting families to come, especially high risk families	Parents can only hold during "holding times" and there can be decreased flexibility with holding when census increased
New and inexperienced nursing staff also contributes to inconsistent communication about FCC and rules which leads to safety concerns	No guideline for implementation of FCC
There is not a true guideline so that everyone is doing the same thing regarding FCC	Parents cannot be present during procedures or resuscitation of infants

Appendix D

Suggestions

Unit in South Dakota	Unit in North Dakota
The care team needs to communicate between each other better to present a more consistent message to the families	Improved staffing ratios to allow nurses to spend more time with families, charge nurse should always be available to help nursing staff or families
Offer parenting classes and provide education to families on what to expect for parental involvement on admission through short videos on FCC	Larger NICU for more space for patients, families and nurses; private rooms
Nursing staff needs to become more proactive with FCC, possibly with more education and scripting	Weekly rounding with families and have a multi-disciplinary team including OT/PT, Dietician, Speech, Lactation, etc.
Decrease medical interventions towards the end of the stay-treat the infant as much as possible like a well newborn as well as have the parents stay overnight	Flexibility in holding times, less strict holding rules, more rooms for parents to “room in” as the infant gets closer to discharge
Greater collaboration with a Child Life Specialist	NICU educator or more education for the nursing staff on FCC
Larger room or community room for crisis situations-such as dying infant so all family can be in the room	Care conferences with long term infants
More consistent caregivers for infants, more assistance from lactation, and a set rounds time	Improved attitudes of staff regarding family involvement
System for updating families who aren’t present during rounds	Staff needs to be more proactive in communicating with families to keep them informed about their infant
Parent support system and suggestions from parents on what we can do better in their infant’s care	More kangaroo care, especially for infants who are stable and doing well
Decrease nurse to patient ratio so that FCC can be better implemented	