

Spring 5-8-2021

Implementation of a Nurse-Led Family Centered Engagement Intervention for Caregivers of Extremely Premature Infants in the Neonatal Intensive Care Unit

Emily Keenan
University of Nebraska Medical Center

Michaela L. Ranallo
University of Nebraska Medical Center

Kathleen A. Walsh
University of Nebraska Medical Center

Haley Chapko

Tiffany A. Moore
University of Nebraska Medical Center

Follow this and additional works at: https://digitalcommons.unmc.edu/con_dnp



Part of the [Maternal, Child Health and Neonatal Nursing Commons](#)

Recommended Citation

Keenan, Emily; Ranallo, Michaela L.; Walsh, Kathleen A.; Chapko, Haley; and Moore, Tiffany A., "Implementation of a Nurse-Led Family Centered Engagement Intervention for Caregivers of Extremely Premature Infants in the Neonatal Intensive Care Unit" (2021). *Doctor of Nursing Practice Projects: College of Nursing*. 1.
https://digitalcommons.unmc.edu/con_dnp/1

This Final Project is brought to you for free and open access by the College of Nursing at DigitalCommons@UNMC. It has been accepted for inclusion in Doctor of Nursing Practice Projects: College of Nursing by an authorized administrator of DigitalCommons@UNMC. For more information, please contact digitalcommons@unmc.edu.

University of Nebraska Medical Center

College of Nursing

DOCTOR OF NURSING PRACTICE (DNP)

IMPLEMENTATION OF A NURSE-LED FAMILY CENTERED ENGAGEMENT INTERVENTION FOR
CAREGIVERS OF EXTREMELY PREMATURE INFANTS IN THE NEONATAL INTENSIVE CARE UNIT

by

Haley Chapko, Emily Nutter, Michaela Ranallo & Kathleen Walsh

The final DNP scholarly project presented to the
Faculty of the University of Nebraska Medical Center College of Nursing

In Partial Fulfillment of the Requirements for the Degree

DOCTOR OF NURSING PRACTICE

May 5, 2020

DNP Program Faculty Academic Advisors: Sue Barnason & Tiffany Moore

Abstract

Objective: The objective of this feasibility study was to examine the implementation and usefulness of a nurse-led engagement intervention for extremely premature infant (EPI) caregivers.

Design: A prospective one-arm design feasibility study.

Setting: The study site was Methodist Women's Hospital in Omaha, NE, in their level III newborn intensive care unit (NICU).

Methods: The study was conducted over a 3-month period and consisted of two intervention components. The first component, the Caregiver's Guide, provided handouts for caregivers with anticipatory guidance on developmentally appropriate care for EPI; the second component provided expanded, specific information on the care of EPI. The NICU nursing staff utilized the Caregiver's Guide to provide education to the caregivers, specific to their EPI.

Results: One caregiver and five NICU staff nurses provided feedback on the Caregiver's Guide. The Usability Surveys completed by the NICU nurses and the caregiver of the EPIs had a mean score of 4.4 out of 5 pertaining to helpfulness. The areas of the Caregiver's Guide that were most utilized by the caregiver (mother) were: environment, ventilation and lines, nutrition, care and touch times, and "ventilation and lines" supporting documents. The caregiver suggested adding content on "quick terms and acronyms" in the Caregiver's Guide. Suggestions from the staff nurses for future application of the Caregiver's Guide included timing of the education, such as specific topics presented on specific day of life as well as specific content emphasized based on nursing shift.

Conclusion: Implementation of the Caregiver's Guide was feasible and was positively received by NICU nurses and caregivers. We recommend implementing a revised version of this tool based on nurse and caregiver feedback into the NICU to improve the knowledge of caregivers of EPI during the first few weeks after birth.

Problem and Significance

Infants born at less than 28-weeks gestation are considered extremely premature infants (EPI) and require several months of care in the Neonatal Intensive Care Unit (NICU). Caregivers of these infants are at an increased risk for posttraumatic stress, anxiety, and depression due to the preterm status of their infant and potential birth complications requiring special care (Helle, Barkmann, Ehrhardt, & Bindt, 2018). The prevalence of perinatal mood or anxiety disorders is higher for NICU parents compared to other parents due to the stressful experiences that accompany a NICU stay (Hatters Friedman et al., 2013; Helle et al., 2018; National Perinatal Association, 2018; Segre, McCabe, Chuffo-Siewert, & O'Hara, 2015).

When a baby is born prematurely, the infant's growth is interrupted as well as the process of preparing for parenthood by the parents (Samra et al., 2015; Stefana & Lavelli, 2016). Not only are these infants premature, but in this sense, the parents are also premature (Stefana & Lavelli, 2016). These parents need immediate and continued education and support to help them transition into NICU life (Craig, Glick, Phillips, Smith, & Browne, 2015; Samra et al., 2015; Stefana & Lavelli, 2016). Parent-infant interaction in the NICU has been well-documented to improve the infants' cardiorespiratory and sleep stability, neurodevelopmental outcomes, breastfeeding, and maternal attachment (Skene et al., 2018). Previous research has found that encouraging skin-to-skin contact and supporting parental involvement in infant care is crucial to the well-being of the infant and promotes mother/infant attachment (Samra et. al., 2015; Stefana & Lavelli, 2016).

When parents are provided the opportunity to help care for their infant, they become more responsible, engaged, and familiar with their infant. When caregivers shift from a passive role to an active role in infant cares, they become more engaged with the infant, more confident in their parenting, and feel a greater sense of control (Craig et al., 2015; Obeidat et al., 2009; Skene et al., 2015). With support and education from nursing staff, parental engagement can improve, and parents can become confident in caring for their infant during their NICU stay (Craig et al., 2015).

This Family-Centered Engagement (FCE) intervention was based on evidence of family-centered developmental care involving family/caregivers as “an essential contributor to the provision of individualized, developmentally supportive care of their baby; this provides a strong supportive foundation for families in the NICU and helps to develop and optimize a lifelong relationship between caregivers and their babies,” (Craig et al., 2015, p. 1). The content for the Caregiver’s Guide was developed using the recommendations by Craig et al. (2015) for involving the family in the care of the NICU patient. An infographic design was the basis for the design of the Caregiver’s Guide. Infographics are visual representations of information using graphics that aid understanding by making data more easily understood. Infographics are useful and innovative forms of communication that may make healthcare information more readily available to the general public; they also enhance our ability to comprehend and make decisions (McCrorie, Donnelly, & McGlade, 2016). The goal of the Caregiver’s Guide content and design was purposefully presented in an infographic-like manner to enhance the uptake of the content for more meaningful caregiver engagement with the infant.

The FCE intervention was comprised of two components: a) a master document, called the Caregiver's Guide, that included anticipatory guidance on developmentally appropriate care for the EPI and information on the NICU experiences; and b) supplemental documents which expanded on specific talking points within the master document. The topics in the Caregiver's Guide included education on multiple components of the NICU such as equipment, procedures, and care of the infant. The NICU nurses used the Caregiver's Guide to provide "talking" points for caregiver education pertaining to the EPI. By learning about the infant's development, environment, and NICU terminology, we hypothesized that the caregiver would be more likely to connect and engage with their baby at the bedside, as well as be more competent in caring for the infant in the NICU.

Purpose and Aims

The purpose of this study was to examine the usefulness of a nurse-led intervention to engage caregivers of premature infants. The aims of this study were to:

1. Determine the feasibility of implementing the nurse-led EPI caregiver engagement intervention.
2. Evaluate the usefulness of a nurse-led EPI caregiver engagement intervention in the Neonatal Intensive Care Unit (NICU).
3. Examine the interrelationships between EPI maternal caregiver perceptions of intervention usefulness, -parent engagement, and maternal anxiety.

Methods

A prospective one-arm design was used for this feasibility study examining the usefulness of a nurse-led engagement intervention for extremely premature infant (EPI) caregivers. The study was conducted over a 3-month. The study site was Methodist Women's Hospital, which has a level III NICU located in Omaha, NE. There are 51 NICU patient beds staffed by approximately 120 bedside NICU nurses. The study site averages three EPI born per month. Inclusion criteria for caregivers included: a) mothers and caregivers of the EPI born less than 28-weeks duration, b) ≥ 19 years old and c) able to speak and read English. Inclusion criteria for NICU nurses included: a) staff nurse in NICU that provides care to EPI and b) ≥ 19 years old.

This intervention was comprised of two components. The first component, the Caregiver's Guide, included anticipatory guidance on developmentally appropriate care for the EPI and information on the NICU experiences. The second component, which included supplemental documents, expanded on specific talking points within the master document. The NICU nurses used the Caregiver's Guide to provide talking points for family education pertaining to the EPI.

Measurements

Feasibility and usefulness of the nurse-led FCE intervention.

Feasibility was measured by the Nurse-led FCE Intervention Feasibility and Usability Survey (Appendix B). The NICU nurse survey delineated components of the Caregiver's Guide he/she used during interactions with the patient's support system. The nurse then ranked their perceived usefulness of the Caregiver's Guide utilizing the Likert Scale and provided additional comments on strengths and areas of growth for the tool.

Caregiver perceptions of FCE nurse-led intervention.

Caregivers provided with the Caregiver's Guide during their stay were interviewed by a research nurse using the Usefulness of FCE Intervention: Caregiver Script (Appendix C). The research nurse conducted rounds at the study site to query caregivers who had received the Caregiver's Guide. The research nurse asked the caregiver the questions on the guide(s) at the bedside, their relationship to the patient, standard "yes" or "no" questions, as well as open-ended questions inquiring the caregiver's most useful topic and what topics they would like to see added.

Procedures for NICU nurses.

All staff NICU nurses who cared for an EPI and utilized the Caregiver's Guide were asked to use the Nurse-led FCE Intervention Feasibility and Usefulness tool (Appendix B). The Nurse Feedback Survey was completed by the bedside nurses weekly during the study period. This survey was printed by the nurse from their e-mail and extra copies of the survey were available in the NICU breakroom. The bedside nurses filled out his/her survey based upon their experience with the Caregiver's Guide. The bedside nurses ranked their perceived usefulness (1 [not helpful] through 5 [very helpful]) of the Caregiver's Guide utilizing the Likert Scale in the Nurse-led FCE Intervention Feasibility and Usability Survey. Lastly, the nurses commented on what they found most useful about the tool. Once the bedside nurse had anonymously filled out the nurse feedback survey, it was placed in a specified collection box within the Methodist Women's NICU breakroom.

Education and training for NICU nurses.

Educating NICU nurses on the use of the Caregiver's Guide and implementation with family was important for success and implementation of the study. Education and training of staff included:

1. An educational module was distributed via email to NICU nurses at the study site who would be participating in the implementation of the nurse-led FCE intervention. The educational materials included a copy of the Caregiver's Guide, a detailed outline of the information contained in the Caregiver's Guide for the bedside nurse to use, and a tip sheet for utilizing the Caregiver's Guide as part of their daily NICU nursing practice with EPI caregivers.
2. The educational materials were displayed in the breakroom/conference room of the NICU at the study site for reinforcement of the nurse-led FCE intervention. The Research Nurse conducted rounding during the study period to answer questions regarding implementation of the intervention, including integrating the Caregiver's Guide into daily nursing interactions with the infant's family and caregivers.

Procedures for caregivers.

This intervention was piloted by NICU staff currently employed at the study site. After the mother was discharged from the hospital and was at the bedside of the EPI, the research nurse recruited the caregiver to participate in the study. The teach-back method was used to verify understanding prior to informed consent was obtained. After enrollment, the bedside nurse provided the Caregiver's Guide and reviewed the information with the caregiver. The Caregiver's Guide was left in the infant's room while the information was still pertinent to the infant for the caregiver to reference as needed. The bedside nurse on each shift referenced

back to the Caregiver's Guide as questions arose from the primary caregiver who was at the bedside.

To obtain caregiver feedback, the bedside nurse asked about the caregiver's perception of the Caregiver's Guide by interview using the Usefulness of the FCE Intervention Script (Appendix C). The research nurse who conducted the interview had the Caregiver's Guide available for the caregiver to review during the interview. The research nurse asked the caregiver questions about the guide at the bedside, their relationship to the patient, standard "yes" or "no" questions, as well as open-ended questions inquiring the caregiver's most useful topic and what topics they would like to see added.

Caregiver's Guide

The Caregiver's Guide consisted of one main document and three supporting documents (Appendix A). The main document was an 8x10 printed guide, consisting of seven topics that were summarized and age appropriate for infants born at less than 28-weeks gestation. The topics summarized included *Environment, Brain Growth, Neuroprotection, Pain and Comfort, Ventilation and Lines, Nutrition, Cares and Touch Time*. Three of the topics (*Environment, Ventilation and Lines, Cares and Touch Time*) had additional support documents on 5x7 inch printed guides (Appendix A). The Caregiver's Guide was kept at the infant's bedside for caregivers to review and discuss with the NICU nurse throughout the infant's hospitalization.

Findings

Two patients were involved in this study. The patients were twins born at less than 28 weeks gestation. One caregiver was surveyed at the end of the study period. Five NICU staff nurses who cared for these patients on a regular basis completed a survey to gather data regarding the feasibility and usefulness of the Nurse-Led FCE Intervention.

Feasibility and Usefulness of the Nurse-Led FCE Intervention

Five staff nurses completed the Usability Surveys with a mean score of 4.4 out of 5 pertaining to helpfulness. The nurses were able to comment on what they found most useful about the tool. One of the bedside NICU nurses recommended to “designate days of life to go over information.” Another staff suggestion was to have the day shift RNs talk/educate on half of the topics, while the night shift RNs educated on the other half. The last comment stated that it was not easy to utilize the Caregiver’s Guide when the patient is critically ill.

Caregiver Perceptions of FCE Nurse-led Intervention

The mother of the EPIs used the Caregiver’s Guide every week. The areas of the Caregiver’s Guide that were most utilized were for the mother were: environment, ventilation and lines, nutrition, care and touch times, and “ventilation and lines” supporting documents. The mother stated that the ventilation and lines topic was the most useful “I referred to that most because our little ones’ lungs were still developing. They were all very helpful though”. Another section that was mentioned in the survey was the nutrition section. The mother stated it pertained to her children daily and there was a lot of back and forth between total parenteral nutrition (TPN) and mother’s breastmilk (MBM).

One suggestion from the caregiver to improve the Caregiver's Guide was to include a "quick terms and acronyms section." The mother thought an area to reference all the medical jargon that the nurses and doctors used would be helpful.

A full analysis of caregiver perceptions of intervention usefulness, parent engagement, and maternal anxiety was unable to be completed due to a small sample size and feedback from only one caregiver.

Discussion

The purpose of this study was to provide education and information to the parents of EPI in the NICU. Education was provided to the caregiver by the bedside NICU nurse in the form of a "Caregiver's Guide" which included handouts containing written information and pictures. The NICU nurses who cared for the infants were surveyed at the end of the study period to provide feedback related to using the tool. The caregiver of the patients was also surveyed for feedback related to the use of the Caregiver's Guide. Overall, the guide was highly rated by the caregiver and nursing staff as being helpful in aiding conversation and education regarding the EPI.

Suggestions by the five NICU nurses included designating certain education to be presented by the dayshift nurse and certain education to be presented by the nightshift nurse. This recommendation was made due to caregivers getting overwhelmed and would alleviate one nurse from providing all the education at one time. Another suggestion from the nursing staff was to assign when certain education should be provided to the caregiver, depending on the day of life of the patient. This also would alleviate burden of staff and reduce information overload for caregivers. Staff could

include a plan of care for the education and document when information was discussed in depth. The bedside nurse could provide new information that pertains to the EPI as they grow and their needs change. Lastly, the nurses reported that the tool was difficult to utilize when the patient was critically ill. Consideration of patient status and prioritizing the information given to the parent also needs to be considered by staff. For example, if a patient is critical, education is difficult for the staff to give and for the caregiver to receive.

The caregiver reported that all the topics included in the Caregiver's Guide were "very helpful" and suggested that the guide provide a reference to the medication jargon and acronyms used in the NICU. Educating and supporting the caregivers of EPI allows them to feel included in the care of the patient, empowers them with knowledge of how to care for their new infant, and prepares them to care for the infant independently when they are discharged home. Being educated on how to care for their new infant can help alleviate anxiety of the parents, allowing them to take part in caring for the infant in the NICU. Caring for their infant is believed to improve bonding, reduce anxiety, and reduce the incidence of post-partum depression. Furthermore, allowing parents to participate in the care of their newborn has shown to have a positive impact on the health of the infant (Skene et al., 2018).

A strength of this study was the number of nurses who were able to care for the patients, educate the caregiver and give feedback on the Caregiver's Guide tool. Having several nurses care for the infants in this study allowed a larger number of staff to utilize the tool and provide feedback on the strengths and weaknesses of the tool. A major limitation of this study was the sample size. Due to a short study period and a small sample size, only one caregiver was able to give feedback, related to the two patients. The small sample size limits the amount

of feedback received about the Caregiver's Guide tool. This limits the suggestions for how to improve the tool and only allows for the perspective of a limited number of nurses and caregivers and the ability to test for aim 3 on relationships with caregiver anxiety.

Conclusions

This feasibility study consisted of two components providing general and specific information for caregivers of EPI. The first component, named the Caregiver's Guide, provided handouts for caregivers with anticipatory guidance on developmentally appropriate care for EPI; the second component provided expanded, specific information on the care of EPI. Overall, this study was feasible and received positive feedback from both the nursing staff in the NICU and the caregiver of the EPI.

Recommendations

The Caregiver's Guide tool should be modified to include the suggestions provided by the individuals who participated in this study. The information provided by the Caregiver's Guide should be designated to be given on certain days of life of the patient, instead of all the information being given at one time. The delivery of education should be divided between dayshift and nightshift bedside nurses so that one nurse is not responsible for providing all the information. The education should be categorized by the gestational age and day of life of the EPI and only given when it is pertinent to the care of the child. Separating who gives the information and when it is given can prevent both the nurse and the caregiver from feeling overwhelmed. Per a recommendation from the caregiver, a section should be added to the

Caregiver's Guide to include a quick reference guide for the medical jargon used by the physicians and nurses in the NICU.

This tool should be implemented in the NICU to improve the knowledge of caregivers of EPI and prepare them to care for their infant after discharge from the NICU. This tool can ease anxiety of caregivers by empowering them with knowledge which can support bonding with their new infant. Parent-infant bonding has been shown to reduce anxiety and improve outcomes of the infant. This tool is simple but provides a wealth of knowledge in a way that caregivers can understand and help ease them into caring for their infant.

References

- Afand, N., Keshavarz, M., Fatemi, N. S., & Montazeri, A. (2017). Effects of infant massage on state anxiety in mothers of preterm infants prior to hospital discharge. *Journal of Clinical Nursing, 26*(13–14), 1887–1892. <https://doi-org.library1.unmc.edu/10.1111/jocn.13498>
- Almeida, F. A., & Brito, F. A. (2014). Planning and evaluating health programs: contributions of the RE-AIM framework to nursing. *Revista latino-americana de enfermagem, 22*(4), 527–528. <http://doi.org/10.1590/0104-1169.0000.2447>
- American Academy of Pediatrics. (2019). Edinburgh Postpartum Depression Scale [PDF]. Retrieved from <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/practicing-safety/Documents/Postnatal%20Depression%20Scale.pdf>
- Brouwers, E. P. M., Van Baar, A. L., & Pop, Victor J. M. (2001). Does the edinburgh postnatal depression scale measure anxiety? *Journal of Psychosomatic Research, 51*(5), 659-663. [https://doi.org/10.1016/S0022-3999\(01\)00245-8](https://doi.org/10.1016/S0022-3999(01)00245-8)
- Cauli, G., Iapichino, E., Rucci, P., Quartieri Bollani, M., Marconi, A. M., Bassi, M., & Gala, C. (2019). Promoting the well-being of mothers with multidisciplinary psychosocial interventions in the perinatal period. *Journal of Affective Disorders, 245*, 148–156. <https://doi-org.library1.unmc.edu/10.1016/j.jad.2018.12.028>
- Centers for Disease Control and Prevention. (2019). Reproductive health: depression among women. Retrieved from <https://www.cdc.gov/reproductivehealth/depression/index.htm>
- Closa-Monasterolo, R., Gispert-Llaurado, M., Canals, J., Luque, V., Zaragoza-Jordana, M., Koletzko, B., & Escribano, S. (2017). *Journal of Maternal Child Health, 21*(7), 1563-1572

- Craig J. W., Glick, C., Phillips, R., Hall, S. L., Smith, J., & Browne, J. (2015). Recommendations for involving the family in developmental care of the NICU baby. *Journal of Perinatology*, 35(Suppl 1), S5-S8. <https://doi-org.library1.unmc.edu/10.1038/jp.2015.142>
- Dilshad, R. M., & Latif, M. I. (2013). Focus group interview as a tool for qualitative research: An analysis. *Pakistan Journal of Social Sciences*, 33(1), 191-198. <http://doi.org/10.1007/BF00987314>
- Faul, F., Erdfelder, E., Lang, A., & Buchner, A. (2007). GPower3: A flexible statistical power analysis program for the social, behavioral and biomedical sciences. *Behavior Research Methods*, 39(2), 175-191. <http://doi.org/10.3758/BF03193146>
- Glasgow, R. E., & Estabrooks, P. E. (2018). Pragmatic applications of RE-AIM for health care initiatives in community and clinical settings. *Preventing Chronic Disease*, 15, 54. <http://doi.org/10.5888/pcd15.170271>
- Hatters Friedman, S., Kessler, A., Nagle Yang, S., Parsons, S., Friedman, H., & Martin, R. J. (2013). Delivering perinatal psychiatric services in the neonatal intensive care unit. *Acta paediatrica*, 102(9), 392-397. <https://doi-org.library1.unmc.edu/10.1111/apa.12323>
- Helle, N., Barkmann, C., Ehrhardt, S., & Bindt, C. (2018). Postpartum posttraumatic and acute stress in mothers and fathers of infants with very low birth weight: Cross-sectional results from a controlled multicenter cohort study. *Journal of Affective Disorders*, 235, 467-473. <https://doi-org.library1.unmc.edu/10.1016/j.jad.2018.04.013>
- Hertzog, M. (2008). Considerations in determining sample size for pilot studies. *Research in Nursing & Health*, 31, 180-191. Retrieved from

[http://search.ebscohost.com.library1.unmc.edu:2048/login.aspx?direct=true&db=cin20
&AN=105737884&login.asp&site=ehost-live&scope=site](http://search.ebscohost.com.library1.unmc.edu:2048/login.aspx?direct=true&db=cin20&AN=105737884&login.asp&site=ehost-live&scope=site)

Matthey, S., Fisher, J., & Rowe, H. (2003). Using the edinburgh postnatal depression scale to screen for anxiety disorders: Conceptual and methodological considerations. *Journal of Affective Disorders*, 146(2), 224-230. <http://doi.org/10.1016/j.jad.2012.09.009>

McCrorie, A. D., Donnelly, C., & McGlade, K. J. (2016). Infographics: healthcare communication for the digital age. *The Ulster medical journal*, 85(2), 71-5.

Mounts, K. O. (2009). Screening for maternal depression in the neonatal ICU. *Clinical Perinatal*, 36(1), 137–152. <https://doi-org.library1.unmc.edu/10.1016/j.clp.2008.09.014>

National Institute of Mental Health. (2019). Postpartum depression facts. Retrieved from <https://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml>

National Perinatal Association. (2018). Supporting your perinatal and mental health wellbeing. Retrieved from http://www.nationalperinatal.org/mental_healthNIMH.

Obeidat, H. M., Bond, E. A., & Callister, L. C. (2009). The parental experience of having an infant in the newborn intensive care unit. *The Journal of perinatal education*, 18(3), 23–29.

<http://doi.org/10.1624/105812409X461199>

Rinehimer, Maureen A. (2017). Investigating the needs of parents of premature infants' interaction in the neonatal Intensive care unit. *Seton Hall University Dissertations and Theses (ETDs)*, 2311. <https://doi.org/scholarship.shu.edu/dissertations/2311>

Sabnis, A., Fojo, S., Nayak, S. S., Lopez, E., Tarn, D. M., & Zeltzer, L. (2019). Reducing parental trauma and stress in neonatal intensive care: systematic review and meta-analysis of

hospital interventions. *Journal of Perinatology*, 39(3), 375–386. <https://doi-org.library1.unmc.edu/10.1038/s41372-018-0310-9>

Samra, H. A., McGrath, J. M., Fischer, S., Schumacher, B., Dutcher, J., & Hansen, J. (2015). The NICU parent risk evaluation and engagement model and instrument (PREEMI) for neonates in intensive care units. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing*, 44(1), 114–126. <https://doi-org.library1.unmc.edu/10.1111/1552-6909.12535>

Segre, L. S., McCabe, J. E., Chuffo-Siewert, R., & O'Hara, M. W. (2014). Depression and anxiety symptoms in mothers of newborns hospitalized on the neonatal intensive care unit. *Nursing research*, 63(5), 320–332. <http://doi.org/10.1097/NNR.0000000000000039>

Skene, C., Gerrish, K., Price, F., Pilling, E., Bayliss, P., & Gillespie, S. (2019). Developing family-centered care in a neonatal intensive care unit: An action research study. *Intensive & Critical Care Nursing*, 50, 54–62. <https://doi-org.library1.unmc.edu/10.1016/j.iccn.2018.05.006>

Stefana, A., & Lavelli, M. (2016). Parental engagement and early interactions with preterm infants during the stay in the neonatal intensive care unit: protocol of a mixed-method and longitudinal study. *BMJ Open*, 7(2), 1-8. <http://doi.org/10.1136/bmjopen-2016-013824>

Appendices


Appendix A: Caregiver's Guide and Supplemental Sheets

Caregiver's Guide- Front

Getting To Know Your Baby

Babies Born Before 28 Weeks Gestation


A HELPFUL INTRODUCTION INTO NICU LIFE AND INFANT DEVELOPMENT




Environment

- * For the length of your stay, your baby will be continually monitored for heart rate, respiratory rate and oxygen saturation.
- * Your baby will be visited by a neonatologist every day of their stay.
- * Your baby's care team will conduct "rounds" daily, which is when they meet to discuss all aspects of their care.
- * Parents are encouraged to share any questions or concerns during this time.

Brain Growth




- * Periods of uninterrupted sleep allow for your baby's brain to grow and develop.
- * If possible your baby should not be disturbed while sleeping.



Neuroprotection

- * Keep the lights dim in your room.
- * Keep the incubator covered to block direct light.
- * Maintaining a quiet room.
- * Minimize the use of perfumes, colognes, or scented lotions.

Pain and Comfort



- * Your nurse will utilize the Neonatal Pain Agitation Sedation Scale (NPASS) to assess your baby's pain.
- * You can help lessen your baby's pain by utilizing:
 - o Sucrose - given on the pacifier.
 - o Sensitive to touch and containment 5 seconds before the start of cares.
 - o Offering a pacifier if cueing.
 - o Scent cloth.

**Use of this "guide" is not permitted without the permission of the authors.

Caregiver's Guide- Back

Getting To Know Your Baby

Babies Born Before 28 Weeks Gestation



Ventilation and Lines

- * Your baby's lungs are still growing and may require the help of an endotracheal tube.
- * The ET tube is hooked to a ventilator to help your baby breathe easily.
- * There are two different types of ventilators you may see in your baby's room:
 - o HFOV
 - o Aavea
- * These vents have different levels of support based on your baby's condition; your nurse or respiratory therapist would be happy to help explain the different ventilator settings and how they help support your baby.
- * Your baby may have a line to receive medications, nutrition or to help monitor their blood pressure.
- * A line can be placed in a vein or artery through the belly button (an umbilical catheter), or a vein in their arm or leg (Peripherally inserted central catheter, or PICC line)

Nutrition



- * Your baby will receive nutrition through their line until their stomach is able to tolerate breast milk or formula.
- * Nutrition will be given through the line in two forms:
 - o Total Parenteral Nutrition (TPN)
 - o Lipids
- * Mothers are still encourage to pump during this time to build up their milk supply.
- * Lactation consultants are available to help with a pumping schedule and tips to increase milk supply.




Cares and Touch Time

- * Cares are set times where you can help the nurse with hands on 'care' to the baby.
- * You are welcome to assist with taking the temperature, changing the diaper and oral care.
- * Skin-to-skin time.

*** ALL ACTIVITIES ARE BASED ON THE BABY'S CONDITION ***

Environment: Supplemental Guide- Front




Environment

Getting To Know Your Baby
A HELPFUL INTRODUCTION INTO NICU LIFE AND INFANT DEVELOPMENT

- Your baby will be continuously monitored while in the NICU.
 - Heart rate
 - Respiratory Rate
 - Oxygen Saturation
 - Blood pressure
- Various alarms may sound, and there may be some common terms you will hear your medical team use:
 - o Bradycardia - heart rate less than 100
 - o Tachycardia - heart rate over 200
 - o Desaturation - oxygen saturation below 90
 - o Tachypnea - respiratory rate over 65
- Your baby will be visited by a neonatologist every day of their stay. This interaction is referred to as 'rounds' and typically occurs in the morning/early afternoon.
- During rounds, your baby's care team meets to discuss all aspects of their care. Parents are an extremely valuable part of the care team and are encouraged to share any questions or concerns during this time.
- If you are not available to speak face-to-face with the neonatologist during rounds, they will be contacting you via phone to talk about any changes being made to your baby's care.

* Disclaimer: Use of this "guide" is not permitted without permission of the authors

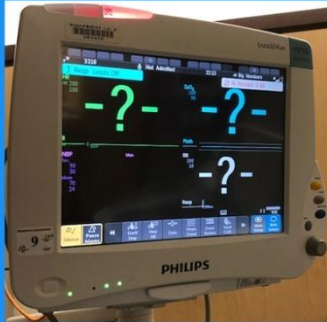
Environment: Supplemental Guide- Back



Environment


Getting To Know Your Baby
A HELPFUL INTRODUCTION INTO NICU LIFE AND INFANT DEVELOPMENT

- Heart rate (green): How fast the baby's heart is beating per minute
- Respiratory Rate (white): How many breaths the baby takes per minute
- Oxygen Saturation (blue): The amount of oxygen in the baby's blood
- Blood pressure (pink): The pressure of the blood pumping through the baby's body



* Disclaimer: Use of this "guide" is not permitted without permission of the authors

Ventilation and Lines: Supplemental Guide- Front




Ventilation and Lines

Getting To Know Your Baby
A HELPFUL INTRODUCTION INTO NICU LIFE AND INFANT DEVELOPMENT

- **Most babies less than 28 weeks require respiratory support. Support is provided through an ET Tube (endotracheal tube) that allows air to be moved in and out of the lungs with minimal effort from the baby.**
- **Respiratory support is provided via ventilators.**
- **Lines in their belly button will be how your baby receives medications, nutrition and to monitor their internal blood pressure.**
 - **Umbilical venous catheter (UVC)**
 - **Umbilical arterial catheter (UAC)**
 - **Peripherally inserted central catheter (PICC)**

*Disclaimer: Use of this "guide" is not permitted without permission of the authors


Ventilation and Lines: Supplemental Guide- Back



Ventilation and Lines

Getting To Know Your Baby
A HELPFUL INTRODUCTION INTO NICU LIFE AND INFANT DEVELOPMENT

- **Respiratory support is provided via ventilators**
 - **HFOV: continuous breaths and have a "jiggle" and cannot be held while on the oscillator.**
 - **Avea**
 - **SIMV - breaths at a controlled rate and controlled pressures.**
 - **NIMV - will give them breaths and pressure to keep their lungs expanded.**
 - **CPAP - little extra assistance with positive pressure.**



*Disclaimer: Use of this "guide" is not permitted without permission of the authors

Cares and Touch Time: Supplemental Guide



Cares and Touch Time

Getting To Know Your Baby

A HELPFUL INTRODUCTION INTO NICU LIFE AND INFANT DEVELOPMENT

- **“What are cares and what can I do?”**
Cares are set times that the parent, nurse and baby interact by providing hands on ‘care’ to the baby. During this time, the nurse will do their assessment of the baby and parents are encouraged to assist with taking the temperature, changing the diaper and oral care.
- **Every evening your baby will be weighed by your nurse. These weight changes will be updated on the whiteboard.**
- **The benefits of skin-to-skin include keeping the baby warm, regulate vital signs, increase bonding and attachment, and decreases the baby’s stress level.**



* Disclaimer: Use of this “guide” is not permitted without permission of the authors

Appendix B: Nurse-Led FCE Intervention Feasibility and Usefulness Survey

Have you used the Caregiver's Guide this week for this infant?
<input type="checkbox"/> Yes
<input type="checkbox"/> No
Which Areas of the Caregiver's Guide have you used this week for the infant?
<input type="checkbox"/> Main Document
<input type="checkbox"/> Environment
<input type="checkbox"/> Brain Growth
<input type="checkbox"/> Neuroprotection
<input type="checkbox"/> Pain and Comfort
<input type="checkbox"/> Ventilation and Lines
<input type="checkbox"/> Nutrition
<input type="checkbox"/> Care and Touch Time
<input type="checkbox"/> "Environment" Supporting Document
<input type="checkbox"/> "Ventilation and Lines" Supporting Document
<input type="checkbox"/> "Cares and Touch Time" Supporting Document
How helpful was the Caregiver's Guide in aiding your conversation and education with the infant's caregiver?
<input type="checkbox"/> 1 (not helpful) <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 (very helpful)
Who was focus of your caregiver interactions this week?
<input type="checkbox"/> Mother
<input type="checkbox"/> Father
<input type="checkbox"/> Another caregiver (Please specify) _____
Do you have any suggestions for improving the Caregiver's Guide?

Appendix C: Usefulness of the FCE Intervention: Caregiver Script

What is your relationship to the patient?
Did a nurse provide you with the Caregiver's Guide (photographic handout) handout at the beginning of your NICU stay? <input type="checkbox"/> Yes <input type="checkbox"/> No
Did nurses explain the Caregiver's Guide and answer questions for you? <input type="checkbox"/> Yes <input type="checkbox"/> No
Was the language on the Caregiver's Guide easy for you to understand? <input type="checkbox"/> Yes <input type="checkbox"/> No
What was the most useful topic on the Caregiver's Guide? Why?
Is there anything you would have found more helpful?