

REVIEW ARTICLE

Family Centered Care in Promoting Neuroprotective Environment for Preterm Neonates: Quality Standards in Neonatal Intensive Care Unit (NICU)

Sandra Jyothi Saldanha^{1*}, Veena Gretta Tauro²

¹Department of Child Health Nursing, Father Muller College of Nursing, Mangalore, Karnataka, India.

²Masood College of Nursing, Mangalore, Karnataka, India.

*Corresponding author:

Mrs. Sandra Jyothi Saldanha, PhD Scholar, RGUHS; Associate Professor, Department of Child Health Nursing, Father Muller College of Nursing, Mangalore, Karnataka, 575002. E-mail: sanjyothsal28@gmail.com

Received date: November 10, 2022; **Accepted date:** December 19, 2022; **Published date:** January 31, 2023

Abstract

Preterm birth-related challenges have provided evidence related to family-centered care and technological advances. This review article focuses on the family-centered and individualized care approach with its influence on preterm neonatal outcomes globally and in India.

Keywords: Family-centered care, Neuroprotective environment, Individualized care, Preterm, Neonatal intensive care unit, Preterm neonates

Introduction

Neonatal Intensive Care Unit (NICU) as a separate entity begun only in 1960s¹ and the first person to design it was Louis Gluck, in Yale New Haven Hospital in America, 1960.² The focus on providing care in incubators and machines gained prominence in the 1970s, and thereafter concept of developmental care and family involvement in care of neonates' evolved. This individualized developmental care concept was first developed by Heidelise Als.³ Meanwhile in the year 1978, Dr. Edgar Rey and Dr. Hector Martinez in Bogota, Columbia proposed and implemented Kangaroo Mother Care (KMC).⁴ Now, KMC is the norm followed in caring for every hemodynamically stable preterm or low birth weight neonate.³

In India, the NICU setup is mainly based on three levels of care in order to categorize the sick neonates and refer to appropriate referral institutions. The level 3 is mainly for the neonates who are extremely preterm, needing

advanced equipment, neonatologists, and experienced nurses.⁵

Preterm births are increasing as so are the challenges towards their survival. These challenges have led to various researches across the globe. Thus, the improvements in technology with a touch of family bonds crafted based on individualized need of the neonate are the current evolving standards of practice in the NICU.

Preterm Outcomes

Preterm birth is when a baby is born before 37 weeks of pregnancy. It is estimated that around 15 million babies each year are born before term, and is one of the leading cause of mortality in children under the age of five.⁶ Preterm births have increased over the years and the survival rates which were considered to be possible only after 28 weeks of gestation until late 1990s have changed to saving neonates as young as 23 weeks and smaller than 500 gms with a survival rate of 33%.³

Antenatal use of corticosteroids and early surfactant therapy has proved to be a boon in reducing respiratory distress and promoting early lung maturity of the preterm neonates.⁷ Fetal brain development is found to be more active in the third trimester.⁸ Hence, the risk of brain development after birth is directly proportional to the gestation at which the baby is born.⁹ Restoring and improving the cognitive and maturational outcomes of the neonatal brain gave rise to evaluation of various developmental interventions. In this quest of implementation of developmental interventions, family involvement concept has evolved and is striving today.¹⁰

Neurodevelopmental Care Interventions

The concept of neurodevelopment is predominant in current NICU care as the major developments in brain take place at the third trimester, which in the preterm babies is the external environment and not the protective place of the womb. The two interdependent neurologic and sensory systems lead the neurobehavioral and neurosensory responses in the neonates. If the sensory experiences are stressful for their stage, neurodevelopment gets affected.¹¹

One of the risk factors for the development of autism spectrum disorders is early preterm born <32 weeks of gestation. As the long term disabilities can be overwhelming for both parents and children who are prematurely born, promoting a better physical, sensory, nutritional, emotional and social environments can foster positive outcomes in the development.¹² The interventions to promote neuroprotective environment to preterm neonates in the NICU is the most thriving field where many researchers have studied, implemented, and evaluated the outcomes. These interventions mainly focus on promoting a healing environment for the neonate. The key component includes providing skin-to-skin contact of the baby with their parent. Skin-to-skin attachment through kangaroo mother care can facilitate healing environment, gives active role to parents in care, helps develop confidence in handling and positioning the baby, safeguards sleep of the baby through maternal comfort and smell, helps reduce pain and stress, maintains thermoregulation and helps increase milk supply in mother which in turn promotes breastfeeding. Thus, one intervention has numerous advantages and is the foundation for neuroprotective environment.¹³

Symington *et al.*, found limited evidence in their systematic review on the developmental care intervention

benefits in improving infants' intellectual, motor, and behavioural development at the time of discharge. However, no adverse events were noted in this context, and improved neurodevelopmental outcomes have been reported up to 24 months corrected age.¹⁴

Additionally, Orton, Spittle, and their colleagues explored the impact of interventions after discharge on premature infants' cognitive and motor growth in three age groups: infancy (0 to 3 years old), pre-school (3-5 years old), and school (5-13 and 13-18 years old). The study findings showed that early developmental interventions enhanced pre-school and infant cognitive outcomes. This benefit was not sustained by school age. Additionally, developmental treatments did not have much of an impact on motor outcomes during childhood or adolescence.^{15,16}

Evidence Based Family-centred Care (FCC) and Neuroprotection

NICU care like that of adult intensive care units earlier focused on complete isolation and separation between mother and baby until discharge from hospital. This concept found many negative outcomes with regard to well-being of the mother and neonate. The mothers would face more anxiety, post-traumatic stress disorders and depression, while the neonates get affected with social, emotional, behavioural and developmental dysfunctions.^{17,18}

Study by O'Brien *et al.*, showed benefits of involving parents and neonates together in the NICU in terms of confidence and knowledge of mothers, initiation of breastfeeding and improvement in weight gain of the baby.¹⁹ The healthcare team members strive towards quality of life, neuroprotection and integration of the sick baby in a healthy family unit.²⁰

Hence, family-centered care is a partnership between the family and the health care team members in caring for the sick neonate. This partnership must be developed through mutual respect, sharing information and involving families in providing care for their newborn.²¹

Sarin E and Maria A in their qualitative research work framed daily training sessions for parent-attendants of the NICU babies in activities such as skin-to-skin care, cleaning, nesting, feeding and providing personal hygiene to their baby. The outcome expressions from the caregivers were good and happy when compared to feeling of helplessness in previous settings when

parent does not know about the condition of their baby in the NICU. Also the study evaluating the health care providers' perception in involvement of families in care showed favourable attitude in terms of empowerment of parents and reduction in workload on staff.²²

By using standardized family-centered care principles in NICU, provision of developmentally safe place for the babies and a stress free environment for the parents is possible.²³

When NICU setting provides constant support and education to the parents, it is found to foster smooth transition from NICU to home care.²⁴

Vanderveen *et al.*, conducted a comprehensive assessment of early intervention programmes for preterm infants that concentrated on parent education in case of family-centered therapies. The research found studies that made use of a variety of interventions, such as parent education, newborn stimulation by parents, home visits, and individualised developmental care. Early therapies enhanced preterm infants' cognitive and motor skills at 12 and 24 months, according to a meta-analysis of the trials, but their effects were short-lived and did not last until the child reached school age.²⁵

A meta-analysis in determining the developmental outcomes of the neonates with regard to mental developmental index and psychomotor developmental index at the ages 6-12 and 13-24 months showed improvements in the groups where developmental care was implemented. Newborn Individualized Developmental Care and Assessment Program (NIDCAP) interventions in NICU also showed better developmental outcomes in preterm neonates.²⁶

Around 197 preterm children who were born at less than 32 weeks of gestation participated in a research study on the benefits of developmental care in preterm management. These preterm children were then divided into two groups: developmental care (DC) group, which included 78 infants, and standard care (SC) group, which included 119 infants. The developmental care group received family-centered care through the NIDCAP programme, which included unlimited access to parents for 24 hours, skin-to-skin contact with kangaroo mothers, protection of infant sleep, pain management, feeding support and encouragement of breastfeeding, promotion of a healing environment with reduction of environmental stressors, and parents' integration in their child's care. The results showed that

the use of mechanical ventilation, antibacterial drugs and parenteral nutrition significantly reduced in the DC group ($p < 0.001$).²⁷

According to a study by Melnyk *et al.*, the educational behavioural intervention programme called COPE (Creating Opportunities for Parent Empowerment) has an impact on how parents interact with their premature children. The researchers educated moms at several points during their infant's hospitalisation, from admission to discharge, using audiotapes and printed materials. The instructional programme shortened hospital stays and enhanced parental mental health outcomes.²⁸

Browne and Talmi discovered that a brief family-based NICU intervention could improve mother involvement in newborn care, decrease maternal stress in the NICU, and improve mother's awareness of their infant's behaviour.²⁹

In their in-depth case study, Dusing, Van Drew, and Brown analysed a clinical practise, created and executed a new parent education programme in the NICU, and identified tactics to involve parents and improve education of preterm mothers. These tactics included starting parent education early, employing several educational forms, providing educational material in multiple sessions to prevent information overload, and providing educational information one-on-one. The researchers came to the conclusion that early education programmes for parents in NICUs can enhance mother's knowledge, support parents in incorporating developmental activities into their infants' daily routines, and decrease maternal anxiety, enhancing both maternal and newborn outcomes.³⁰

Few studies were conducted in India related to family-centered care in sick neonates and these proved to be beneficial in terms of high exclusive breastfeeding rates.³¹

The financial burden caused by NICU admission also is an added burden for parents having preterm baby. Interesting research work on "Hospital to Home: Optimizing the Preterm infant's Environment (H-HOPE)" interventions on hospitalization charges showed reduction in the cost spent by parents towards their treatment. The H-HOPE interventions included for both mother and the neonate such as individualized participatory guidance towards preterm infants given by trained staff to mothers. The neonates received auditory, tactile, visual and vestibular stimulation.³²

Implementation of Family-centered Care in India

Dr. Ram Manohar Lohia (RML) Hospital in Delhi started a 14 bedded NICU facility in 2012 with the concept of FCC as an informal step and is now believed to be one of the standards of care. Individualized care units for parents with their neonates have shown acceptability by the parents and healthcare providers.²² However, the physical structure needs modification in order to accommodate 24-hour mother/caregiver involvement time with the neonate. This could be a drawback in implementation of the model in other hospitals.

The Ministry of Health and Family Welfare in 2017 has laid operational guidelines towards implementation of FCC in the country, which were initiated in 700 public health facilities.³³ This standard practice needs to reach all the communities and further research is directed.

Conclusion

Family-centered care is a collaboration between the parents and the health care team in decision making, sharing information and mutual respect. In countries like India, FCC can be a boon in improving care as less staff to patient ratio is always a concern towards providing quality care. Also the effective use of resources will reduce the cost of hospitalization.

Considering the short term benefits of family centred care, it is beneficial in caring for mother infant dyad from the very beginning phase in a preterm neonates' life. The long term benefits were not found to be significant in the studies evaluated. However, the parent-infant support has shown better neurodevelopmental outcomes in the neonates.

Conflict of interest

None

References

1. Neonatal intensive care unit. Wikipedia. Last updated 29th December, 2022. (Available at https://en.wikipedia.org/wiki/Neonatal_intensive_care_unit)
2. Gluck L. Conceptualization and initiation of a neonatal intensive care nursery in 1960. In: Neonatal intensive care: a history of excellence. Bethesda, U.S. Department of Health and Human services, Public Health Service, National Institutes of Health; 1992.
3. Payne E. A Brief History of Advances in Neonatal Care [Internet], NICU Awareness, updated Jan 5, 2016 (Available at: <https://www.nicuawareness.org/blog/a-brief-history-of-advances-in-neonatal-care>)
4. Simkiss DE. Kangaroo mother care. *J Trop Paediatr* 1999;(45):192-4.
5. Singh M. Care of the Newborn. 9th ed. New Delhi: CBS Publishers; 2021. p. 4-5.
6. Liu L, Oza S, Hogan D, Chu Y, Perin J, Zhu J, *et al.* Global, regional, and national causes of under-5 mortality in 2000-15: an updated systematic analysis with implications for the Sustainable Development Goals. *Lancet* 2016;388(10063):3027-35.
7. World Health Organization. WHO recommendations on interventions to improve preterm birth outcomes.2015 (Available at: www.who.int/reproductivehealth/publications/maternal_perinatal_health/preterm-birth-guideline)
8. Volpe JJ. Brain injury in premature infants: a complex amalgam of destructive and developmental disturbances. *Lancet Neurol* 2009;8(1):110-24.
9. Altimier LB. Neuroprotective core measure 1: the healing NICU environment. *Newborn Infant Nurs Rev* 2015;15(3):91-6.
10. Sizun J, Westrup B. Early developmental care for preterm neonates: a call for more research. *Arch Dis Child Fetal Neonatal Ed* 2004;89(5):F384-8.
11. Altimier L, Phillips R. The neonatal integrative developmental care model: advanced clinical applications of the seven core measures for neuroprotective family-centered developmental care. *Newborn Infant Nurs Rev* 2016;16:230-44.
12. Altimier L, White R. The Neonatal Intensive Care Unit (NICU) Environment. In: Kenner C, Lott J, eds. *Comprehensive Neonatal Nursing Care*. NY: Springer Publishing; 2014. p. 722-38.
13. Ludington-Hoe S. Kangaroo Care Is Developmental Care. In: McGrath CKJ, ed. *Developmental Care of Newborns and Infants: A Guide for Health Professionals*. Glenview, IL: National Association of Neonatal Nurses; 2010. p. 3.
14. Symington AJ, Pinelli J. Developmental care for promoting development and preventing morbidity in preterm infants. *Cochrane Database Syst Rev* 2006;19(2):CD001814.
15. Orton J, Spittle A, Doyle L, Anderson P, Boyd R. Do early intervention programmes improve

- cognitive and motor outcomes for preterm infants after discharge? A systematic review. *Dev Med Child Neurol* 2009;51(11):851–9.
16. Spittle A, Orton J, Anderson PJ, Boyd R, Doyle LW. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. *Cochrane Database Syst Rev* 2015;2015(11):CD005495.
 17. Brecht C, Shaw R, St John N, Horwitz S. Effectiveness of therapeutic and behavioral interventions for parents of low-birth-weight premature infants: a review. *Infant Ment Health J* 2012;33(6):651–665.
 18. Bernard-Bonnin A, Canadian Paediatric Society. Maternal depression and child development. *Pediatr Child Health* 2004;9(8):575–583.
 19. O'Brien K, Bracht M, Macdonell K, McBride T, Robson K, O'Leary L, *et al.* A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. *BMC Pregnancy Childbirth* 2013;13(Suppl 1):S12.
 20. Altimier L, Phillips R. The neonatal integrative developmental care model: seven neuroprotective core measures for family-centered developmental care. *Newborn Infant Nurs Rev* 2013;13(1):9–22.
 21. Ahmann E, Abraham MR, Johnson BH. Changing the concept of families as visitors: supporting family presence and participation. Bethesda, MD: Institute for Family-centered Care; 2003.
 22. Sarin E, Maria A. Acceptability of a family-centered newborn care model among providers and receivers of care in a public health setting: a qualitative study from India. *BMC Health Serv Res* 2019;184(19):1–11.
 23. Craig JW, Glick C, Phillips R, Hall SL, Browne J. Recommendations for involving the family in developmental care of the NICU baby. *J Perinatol* 2015;35:S5-S8.
 24. Als H, Gilkerson L, Duffy FH, McAnulty GB, Buehler DM, Vandenberg K, *et al.* A three-center, randomized, controlled trial of individualized developmental care for very low birth weight preterm infants: Medical, neurodevelopmental, parenting, and caregiving effects. *J Dev Behav Pediatr* 2003;24(6):399-408.
 25. Vanderveen J, Bassler D, Robertson C, Kirpalani H. Early interventions involving parents to improve neurodevelopmental outcomes of premature infants: a meta-analysis. *J Perinatol* 2009;29(5):343.
 26. Soleimani F, Azari N, Ghiasvand H, Shahrokhi A, Rahmani N, Fatollahierad S. Do NICU developmental care improve cognitive and motor outcomes for preterm infants? A systematic review and meta-analysis. *BMC Pediatr* 2020;20(1):67.
 27. Pavlyshyn H, Sarapuk I, Tscherning C, Slyva V. Developmental care advantages in preterm infants management. *J Neonatal Nurs* 2023;29(1):117-122.
 28. Melnyk BM, Feinstein NF, Alpert-Gillis L. Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. *Pediatrics* 2006;118:e1414–27.
 29. Browne JV, Talmi A. Family based intervention to enhance infant-parent relationships in the neonatal intensive care unit. *J Pediatr Psychol* 2005;30(8):667-77.
 30. Dusing SC, Van Drew CM, Brown SE. Instituting parent education practices in the neonatal intensive care unit: an administrative case report of practice evaluation and state wide action. *Phys Ther* 2012;92(7):967-75.
 31. Verma A, Maria A, Pandey RM, Hans C, Verma A, Sherwani F. Family-centered care to complement care of sick newborns: a randomized controlled trial. *Indian Pediatr* 2017;54(6):455-59.
 32. Vonderheid SC, Park CG, Rankin K, Norr KF, White-Traut R. Impact of an integrated mother-preterm infant intervention on birth hospitalization charges. *J Perinatol* 2020;40(6):858-866.
 33. Child Health Division, Ministry of Health and Family Welfare. Government of India. Family participatory Care for Improving Newborn Health. Operational guidelines for planning and implementation. [Internet] 2017. Available from: https://nhm.gov.in/images/pdf/programmes/child-health/guidelines/Family_Participatory_Care_for_Improving_Newborn_Health-Operational_guideline.pdf