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Review

Parents in the Neonatal Intensive Care Unit of "Hospital de São João" (Porto, Portugal)

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Abstract

The birth of a preterm or a sick infant represents a well-known emotional crisis for parents and family. It has been documented that a multidisciplinary approach to the care of newborns hospitalized in Neonatal Intensive Care Units (NICUs) is essential for the development of these children. The presence of parents 24 hours a day, participating in the care of their children, is a reality in our NICU since its opening in July 1983. Aspects related to the optimization of care for these immature newborns, as well as the relationship between parents and professionals, are also mentioned.

Keywords

Parents, NICU, NIDCAP, neurodevelopmental care, preterm infant.

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Background

Before and during the course of the 19th century, infants were born at home and care was provided by mother and family members. In the last third of the 19th century and the early third of the 20th century, the advances in technology with invention of incubators marked the beginning of the separation of the neonatal care from the family. Out-of-hospital births decreased in the USA from 44% in 1940 to 1% in 1969 and following years and the care of mothers and infants shifted dramatically from at-home to in-hospital [1].

The social changes occurred in the second half of the 20th century, leading to the empowered and informed healthcare consumers, led also to a greater inclusion of parents in the care of their child in the Neonatal Intensive Care Unit (NICU) [2].

The start of Neonatology in Portugal coincided with the transfer of responsibility concerning newborn assistance from Obstetricians to Pediatricians and the recognition of the specialty by the Medical Professionals Association. The development of Neonatology occurred fundamentally in the Sixties, thanks to the prestige of some pioneer figures, the development of primary care to pregnant women and newborns, the distribution of material for newborn resuscitation, the promotion of national and regional education initiatives and the generalization of medical careers to the whole country. The General Administration of Pediatric Primary Healthcare, when defining the basic plan of perinatal care (1974-75) in Portugal, adopted several measures as the Pregnancy Diary and the Child Healthcare Diary, the acquisition and distribution of basic materials for the resuscitation of newborns in State Institutions and the implementation of action-formation initiatives. It was in the Eighties that the first NICUs appeared in Portugal. In the "Hospital de São João", on 5th July 1983, a Neonatology unit was established, with an initial total capacity of eight beds, having actually a total of seventeen beds with nine of intensive care.

There has been a very positive evolution in healthcare activity since the opening of the service until the present day. The progressive increase in the number of patients treated has followed a gradual decrease in mortality rate despite the severity of the condition of patients, since this service is of reference for newborns with cardiac, metabolic and surgical pathologies of Northern Portugal, being necessary sometimes, due to lack of beds in our unit, to transfer preterm newborns and very low birthweight infants from our NICU to another hospital, to receive cardiac and surgical patients.

The progressive improvement of prenatal diagnosis and the creation of the Prenatal Diagnostic Center at "Hospital de São João" in August 2000 has allowed an increasing number of pregnant women with fetal pathology to be oriented to the Obstetrics Service of our Hospital. However, about 35% continue to be born in other hospitals, and these newborns undergo a neonatal transport with the inherent risks.

Among the most relevant milestones in newborn assistance are the first ventilator in 1984 and the creation of the transport of high-risk newborn from the Northern zone in 1988, improving the conditions of newborn transport. In 1996, parenteral nutrition began to be prepared in the hospital pharmacy, with all aseptic conditions, contributing to the reduction of infectious risks inherent to this therapy. In that year the screening of retinopathy of prematurity and the evaluation of hearing and development were initiated as well. Patients have motor and respiratory treatment carried out by technicians specialized in Pediatrics/Neonatology, with a very positive impact on sequels and hence on the quality of life of these newborns. High-risk newborn hospitalization in NICU is lived by parents with a lot of anguish and anxiety, and this is supported by a psychologist on a daily basis since the year 2000.

On 1th June 2007 (International Children's Day), the universal hearing screening started at "Hospital de São João", with the collaboration of Obstetrics, Neonatology and Otorhinolaryngology Services. Neonatal ECMO began to be realized in 2010 and the hypothermia in the hypoxic-ischemic encephalopathy in 2011.

In our NICU, parents are allowed to participate in the care of their babies and stay 24 hours with them from the opening day of our NICU in 1983.

Family- and newborn-centered developmental care

It has been documented that a multidisciplinary approach in the care of newborns hospitalized in NICUs is essential for the development of these children.

The Neonatal Individualized Developmental Care and Assessment Program (NIDCAP) is an integrated and holistic form of family-centered developmental care. It has been implemented in our NICU since 2003. NIDCAP offers an individualized and nurturing approach to the care of infants in NICUs and special care nurseries. This philosophy of care change the traditional NICU towards an early developmental care NICU, with the following actions: training the staff, investing in quality of care, involving parents and keeping them in proximity to their infants to care them. This relationship-based, family-centered approach promotes the idea that infants and their families are collaborators in developing an individualized program of support to maximize physical, mental, and emotional growth, improving the long-term health outcomes for this high risk population [3-7].

Premature infants, mainly those born before the last trimester of gestation, a very important time for

the development of the fetal brain, have a very bad sensory experience in the environment of the units, including exposure to lights, noises, interventions that frequently are stressful and painful; they have also diminished positive experiences [8, 9]. These unexpected challenges to the immature brain during this sensitive period should be taken into account by healthcare providers every day in NICUs.

The role of NIDCAP is to minimize the impact to the immature brain of the over-stimulating environment to improve brain development and long-term outcomes [10-12].

It has been shown that early sensitivity training for parents of preterm infants has impact on the developing brain [13]. Thus, an adequate information given to the parents, breastfeeding support, skin-to-skin holding, parent education seminars, sibling and family support activities, parent-to-parent support, transition to home support, bereavement support, unlimited parent presence, parent participants in care and decision making, parents on rounds, palliative care support, support of specific populations, namely rural and foreign families and adolescent mothers, are some aspects of family-centered care and family support in the NICU.

Culturally sensitive care practices and the physical environment need to be considered to facilitate parent-infant closeness, such as skin-to-skin contact, family-centered care, increased visiting hours, family rooms and optimization of the space on NICUs [14].

The unlimited parent presence in our NICU is a very important aspect of care. Every day parents can help nurses to care for their babies, during the bath, nutrition, changing their position and through Kangaroo care. A very light music and mainly mother voice are always a practice of developmental care in our NICU.

It has been shown that maternal sounds improve autonomic stability and provide a more relaxing environment for the newborns infants [15, 16]. Knowing that preterm newborns respond to maternal sounds with heart rate variations, we realized a study in our NICU to sensitize the staff to different aspects of care (unpublished data).

Nowadays we believe that the family-centered developmental care is the best mode of care. So, each NICU must adopt it recognizing that the newborn infant is a human being with a family. In this new approach of care, both nurses and doctors must be guided by the individual infant and family needs. The role of the medical staff becomes more complex and challenging; however much more rewarding: they moved from task-oriented to relationship-based care, facilitators of bonding and attachment [17].

The possibility of involving parents in the care of their children is provided to them immediately after the admission to the NICU. Since the opening of the NICU, our hospital authorized a free transit for parents, allowing them to assist their children 24 hours/day and, if they want, to stay with them all day. In practice, parents are always accompanied by a nurse, and participate to care according to their will, which usually is associated with their emotional state. Parents are free to decide how far they can go in this partnership care, and the professionals act according to each situation, adopting an individualized and appropriate attitude to each newborn and his/her family.

In cases of serious illness or bereavement, the support of all health professionals including the psychologist is crucial.

The extraordinary advance in Neonatal Medicine allowed the survival of many newborns with severe diseases and an increased number of children live with severe handicaps, becoming a great burden to their parents and families. In these cases, doctors, nurses, psychologists and other parents are all essential to help and support these families.

Perinatal palliative care is a developing model of care aimed at providing supportive services to families anticipating fetal or neonatal demise. End-of-life experiences have been evaluated in several NICUs and perceived as variable and inconsistent [18]. In our NICU, in the last decade, we observed an improvement in practices of end-of-life care for newborns with terminal diseases [19, 20]. There are areas for improvement and it has been reported that a formalized palliative care team could help with an increase in redirection of care and palliative medication usage and a decrease in variability of use of end-of-life interventions [21-23]. In all these cases all actions should be performed taking into account the best interests of the newborn [24].

When a death of a newborn occurs, parents experience one of the most profoundly distressing events. It is not easy for professionals to face these situations; however, respectful care for parents suffering perinatal loss is mandatory. NICU professionals with their knowledge, spirituality and experience help parents to overcome these difficult moments [25]. Our working bereavement group support parents also after discharge if they want.

Role of the psychologist in the NICU – the triade psychologist, parents and professionals

The premature birth of a baby is often felt by the family as a traumatic event. So the family has to face an unexpected and stressful situation. Several studies analyze the behavior and development of newborns demonstrating evidence about possible consequences of premature birth and hospitalization in a NICU [3]. Also the attachment processes have the potential to be delayed or disrupted as a result of the abrupt separation of the dyad premature baby-mother due to the entry in the NICU [26].

Anxiety, depression and trauma symptoms are associated with reaching high levels in stress checklist applied to parents in the NICU [27].

Due to the conditions of organic baby instability and the need for specialized medical care since admission to the NICU, the family experiences the unpredictability of baby's evolution and the fear of insults and eventually the loss.

Added to these difficulties, there are the following situations: the contrast between the ideal baby and the real baby – a premature, with its fragility and vulnerability; the forced reorganization of the mental representation of family, especially the mother's representation, with the activation of new adaptive mechanisms to integrate the image of a very small and fragile child. From this perspective the importance of assessing and supporting maternal feelings is fundamental.

The role of neonatal psychotherapists is a multifaceted one, as they must function as several different specialists in a fast-paced, stressful environment [28]. The psychologists need to be able to be part of a team that provides comprehensive services for developmental, behavioral, and mental health needs of infants, parents, and families. It is also vital that they gain the trust of the medical team and the family, as care is best carried out only when the entire team is involved.

In our unit, parental involvement in the provision of children's care includes: permanency of both parents in the NICU, possibility for grandparents or siblings to visit their baby, support of social service and psychological support (aspects that differ from unit to unit) [29].

Our psychological work develops on two levels (but both at the same time), on the one hand with parents and on the other with the staff. First of all, we focus on the crisis intervention and this moment contains the following elements:

1. mother's problems in remembering and integrating the events involved in childbirth and in the separation of the baby. In this way, it becomes important for her to rebuild the events before and during the birth of the child, as well as during the early days of NICU treatment;
2. support to mothers in understanding their reactions to stress and trauma, in order to realize and integrate their bewildering behaviors as a normal response to a stressful or traumatic event;
3. provision of support during emotional outbursts – particularly in situations of multiple birth, when one baby dies;
4. exploration of mother's coping mechanisms, leading her to think about stressful experiences of the past and re-enable them in the current crisis;
5. exploration of current social support, in order to be used in the current crisis situation;
6. finally, an exploration of possible solutions to concrete problems (e.g., care of other siblings, practical difficulties in professional activity and in everyday life, and efficient solutions).

Besides crisis intervention, further work is carried out, concerning preterm birth and prematurity. In that moment we explore the parental perception of their infant's condition to detect and potentially address preventive strategies. We perform a medical history of pregnancy and birth in order to identify traumatic events that occurred at this stage. We explore the mental representations of fatherhood to identify potential problems and facilitate the connection with the baby and the staff in the NICU environment; we encourage parents to express any criticism and discuss the relationship with their partner and family to identify ways to improve the level of support given. Sporadically, we appeal to pharmacological intervention or referral for psychiatric consultations for the mother.

Parents association in the NICU in Portugal

Two parents associations are present in Portugal, "XXS Association for preterm infants" (created in November 2008) and "Premature Parents" (created in November 2012). Both are formed by a group of parents who lived the experience of preterm birth in first person and support other families facing the same reality. Their mission is to help premature babies and their family to overcome moments that are likely the hardest of their lives, promoting dialogue with the families, supporting parental moments of crisis and facilitating the dialogue with the

professionals. They support parents and families to manage their feelings, stress and anxiety.

Theses associations develop activities in all NICUs in Portugal to help to prevent prematurity, to ensure the best possible treatment care during hospitalization and also to improve the long-term health of preterm infants and newborns with chronic diseases.

The European Foundation of Care of the Newborn Infant (EFCNI) is an organization that includes parents associations, health professionals and scientists and represents the interests of preterm and newborn infants and their families. It works in close collaboration with other perinatal and pediatric scientific societies. Being part of this European organization, all parents associations work internationally [30, 31].

Conclusion

Parents are important members of the care team in NICUs. Nowadays, almost everywhere in the world, parents form parents associations that make a valuable work in supporting parents and families.

We believe that parents should be able to fully participate in the care of their babies, maintaining and improving their relationship with healthcare providers.

The presence of parents in NICUs during hospitalization of their children and the promotion of family-centered care should be the standard of care in the management of these children.

The perinatal and neonatal palliative care and bereavement follow-up are key practical aspects that we would like to improve in the NICU.

Declaration of interest

The Authors declare that there is no conflict of interest.

References

1. Raju TNK. Growth of neonatal-perinatal medicine: a historical perspective. In: Martin RJ, Fanaroff AA, Walsh MC (Eds.). Fanaroff and Martin's Neonatal-Perinatal Medicine, Diseases of Fetus and Infant. 10th Edition. Philadelphia: Elsevier Saunders, 2015, pp. 2-15.
2. Thomson-Salo F. Care of the Long-Stay Infant and Parents. In: Martin RJ, Fanaroff AA, Walsh MC (Eds.). Fanaroff and Martin's Neonatal-Perinatal Medicine, Diseases of Fetus and Infant. 10th Edition. Philadelphia: Elsevier Saunders, 2015, pp. 642-6.
3. Als H. Neurobehavioral development of the premature infant. Avery ME, First LR (Eds.). Pediatric Medicine. Baltimore: Williams and Wilkins, 1994:155-60.
4. Wender E; Committee on Psychosocial Aspects of Child and Family Health. Supporting the family after the death of a child. Pediatrics. 2012;130(6):1164-9.
5. Dobbins N, Bohlig C, Sutphen J. Partners in growth: Implementing family-centered changes in the neonatal intensive care unit. Child Health Care. 1994;23:115-26.
6. Gooding JS, Cooper LG, Blaine AI, Franck LS, Howse JL, Berns SD.Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. Semin Perinatol. 2011;35(1):20-8.
7. Calabretta N, Cavanaugh S, Malone M, Swartz BJ.A hospital-based patient nd family education center: if you build it, will they come? Med Ref Serv Q. 2011;30(1):19-30.
8. Gooding JS, Cooper LG, Blaine AI, Franck LS, Howse JL, Berns SD. Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. Semin Perinatol. 2011;35(1):20-8.
9. Jobe AH. A risk of sensory deprivation in the neonatal intensive care unit. J Pediatr. 2014;164(6):1265-7.
10. Curley JP, Jensen CL, Mashoodh R, Champagne FA. Social influences on neurobiology and behavior: epigenetic effects during development. Psychoneuroendocrinology. 2011;36(3):352-71.
11. Als H, Duffy FH, McAnulty G, Butler SC, Lightbody L, Kosta S, Weisenfeld NI, Robertson R, Parad RB, Ringer SA, Blickman JG, Zurakowski D, Warfield SK. NIDCAP improves brain function and structure in preterm infants with severe intrauterine growth restriction. J Perinatol. 2012;32(10):797-803.
12. Legendre V, Burtner PA, Martinez KL, Crowe TK.The evolving practice of developmental care in the neonatal unit: a systematic review. Phys Occup Ther Pediatr. 2011;31(3):315-38.
13. McAnulty G, Duffy FH, Kosta S, Weisenfeld NI, Warfield SK, Butler SC, Bernstein JH, Zurakowski D, Als H.School Age Effects of the Newborn Individualized Developmental Care and Assessment Program for Medically Low-Risk Preterm Infants: Preliminary Findings. J Clin Neonatol. 2012;1(4):184-94.
14. Milgrom J, Newnham C, Anderson PJ, Doyle LW, Gemmill AW, Lee K, Hunt RW, Bear M, Inder T. Early sensitivity training for parents of preterm infants: impact on the developing brain. Pediatr Res. 2010;67(3):330-5.
15. Flacking R, Lehtonen L, Thomson G, Axelin A, Ahlqvist S, Moran VH, Ewald U, Dykes F. Closeness and separation in neonatal intensive care. Separation and Closeness Experiences in the Neonatal Environment (SCENE) group. Acta Paediatr. 2012;101(10):1032-7.
16. Rand K, Lahav A. Maternal sounds elicit lower heart rate in preterm newborns in the first month of life. Early Hum Dev. 2014;90(10):679-83.
17. Alexandre C, De Jonckheere J, Rakza T, Mur S, Carette D, Logier R, Jeanne M, Storme L. Impact of cocooning and maternal voice on the autonomic nervous system activity in the premature newborn infant. Arch Pediatr. 2013;20(9):963-8.

18. Westrup B. Family-Centered Developmentally Supportive Care. Neoreviews. 2014;15;e325.
19. Guimarães H, Rocha G, Almeda F, Brites M, Van Goudoever JB, Iacoponi F, Bellieni C, Buonocore G. Ethics in neonatology: a look over Europe. J Matern Fetal Neonatal Med. 2012;25(7):984-91.
20. Moura H, Costa V, Rodrigues M, Almeida F, Maia T, Guimarães H. End of life in the neonatal intensive care unit. Clinics (Sao Paulo). 2011;66(9):1569-72.
21. Soares C, Rodrigues M, Rocha G, Martins A, Guimaraes H . End of Life in Neonatology: Palliative Care Integration. Acta Med Port. 2013;26(4):318-26.
22. Younge N, Smith PB, Goldberg RN, Brandon DH, Simmons C, Cotten CM, Bidegain M. Impact of a palliative care program on end-of-life care in a neonatal intensive care unit. J Perinatol. 2014 Oct 23. [Epub ahead of print].
23. Petteys AR, Goebel JR, Wallace JD, Singh-Carlson S. Palliative Care in Neonatal Intensive Care, Effects on Parent Stress and Satisfaction: A Feasibility Study. Am J Hosp Palliat Care. 2014 Sep 16. [Epub ahead of print].
24. Samsel C, Lechner BE. End-of-life care in a regional level IV neonatal intensive care unit after implementation of a palliative care initiative. J Perinatol. 2014 Oct 23. [Epub ahead of print].
25. Guimarães H, Rocha G, Bellieni C, Buonocore G.Rights of the newborn and end-of-life decisions. J Matern Fetal Neonatal Med. 2012;25(Suppl 1):76-8.
26. Donovan LA, Wakefield CE, Russell V, Cohn RJ Hospital-based bereavement services following the death of a child: A mixed study review. Palliat Med. 2014 Nov 13. [Epub ahead of print].
27. Fegran L, Helseth S, Fagermoen MS. A comparison of mothers' and fathers'experiences of the attachment process in a neonatal intensive care unit. J Clin Nurs. 2008;17:810-6.
28. Obeidat HM, Bond EA, Callister LC. The parental experience of having an infant in the newborn intensive care unit. J Perinat Educ. 2009;18:23-9.
29. Vergara ER, Bigsby R. Developmental & therapeutic interventions in the NICU. Baltimore, Maryland: Paul H. Brookes Publishing Co., Inc, 2004.
30. Greisen G, Mirante N, Haumont D, Pierrat V, Pallás-Alonso CR, Warren I, Smit BJ, Westrup B, Sizun J, Maraschini A, Cuttini M; ESF Network. Parents, siblings and grandparents in the Neonatal Intensive Care Unit. A survey of policies in eight European countries. Acta Paediatr. 2009;98(11):1744-50.
31. http://www.efcni.org/, last access: March 2015.
32. http://www.uenps.com/, last access: March 2015.