



Topic Expert Group: Infant- and family-centred developmental care

Family access

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Target group

Infants, parents, and families

User group

Healthcare professionals, neonatal units, hospitals, and health services

Statement of standard

Parents (and substitutes designated by the parents) have continuous access and are able to remain with the infant throughout the 24 hours.

Rationale

Throughout Europe there is evidence that parents do not have 24-hour access to their infant. (1–3) Early separation is harmful for both newborn infants and their parents, since it disrupts the biological and emotional bonding that has developed already during gestation. (4,5) Separation between parents and infants has short- and long-term consequences. This acts as a stressor with effects on the physical and mental health for both the infant and family, it may interfere with breastfeeding, and alter the bonding and attachment process. Researchers have suggested that parent engagement in the NICU has the potential to be a low cost, high quality intervention with a positive influence on the health outcomes of preterm or ill infants and their parents. (6)

Thus, there is a clear rationale to have the neonatal units open throughout the 24 hours for parents (or by them designated substitutes) and to provide facilities for parents and family members to stay with the infant without interruption in, or adjacent to the neonatal unit.

Benefits

Short-term benefits

- Improved parent-infant bonding (7)
- Increased breastfeeding rates (8)
- Longer skin-to-skin contact (9)
- Reduced short-term pulmonary morbidity (10)
- Improved feeding (11) and weight gain (12)
- Reduced stress for infants (13)
- Increased neuro-behavioural stability in preterm infants (14)
- Increased parental involvement (14,15)
- Reduced length of stay in the NICU (10,14,16)



Long-term benefits

- Improved parent-infant interaction following discharge (17)
- Reduced rates of readmission following NICU discharge (18)
- Reduced costs of NICU hospitalisation (17)
- Improved parental mental health (11,16,19–22)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and family		
1. Parents and family are informed by healthcare professionals about the importance of being present and being the primary care giver during neonatal care. (23)	B (High quality) C (High quality)	Patient information sheet
2. Parents (or family designated substitutes) are educated and supported to be the primary care givers during neonatal care by healthcare professionals. (10,23) (see TEG Infant- & family-centred developmental care)	A (Moderate quality) B (Moderate quality) C (High quality)	Guideline, parent feedback, training documentation
For healthcare professionals		
3. A unit guideline on 24-hour access for parents (or family designated substitutes) without interruption during rounds, shift changes and procedures is adhered to by all responsible healthcare professionals. (10)	A (Moderate quality) B (High quality)	Guideline, parent feedback
For neonatal unit		
4. A unit guideline on 24-hour unit access for parents (or family designated substitutes) and solutions to meet confidentiality needs is available and regularly updated. (10) (see TEG NICU design)	A (Moderate quality) B (High quality)	Guideline, parent feedback
For hospital		
5. The 24-hour access to the hospital building is authorised for parents (or family designated substitutes). (10)	A (Moderate quality) B (Moderate quality)	Guideline, parent feedback
For health service		
6. A national guideline on 24-hour access to neonatal units is available and regularly updated and supported by	A (Moderate quality) B (High quality)	Guideline



national professional societies and
health ministries. (10)

Where to go – further development of care

Further development	Grading of evidence
For parents and family N/A	
For healthcare professionals	
<ul style="list-style-type: none">Support access to neonatal units for siblings and other relatives.	B (Moderate quality)
For neonatal unit and hospital	
<ul style="list-style-type: none">Develop and support the availability of Couplet Care (concomitant care of infant and mother in need of medical care in the same ward/unit).	B (Moderate quality)
For health service	
<ul style="list-style-type: none">Develop a policy of Couplet Care.	A (Low quality) B (Moderate quality)

Getting started

Initial steps

For parents and family

- Parents and family are verbally informed by healthcare professionals about the importance of being present and being the primary care giver during neonatal care.
- Parents are encouraged to spend as much daily time as possible with direct physical access to their infant over several feeding and caring times.

For healthcare professionals

- Promote meetings with all caregivers to discuss attitudes, barriers and concrete solutions to establish access throughout the 24 hours in the NICU for parents.

For neonatal unit and hospital

- Develop and implement a unit guideline on opening of the NICU throughout the 24 hours for parents (or designated substitutes).

For health service

- Develop and implement a national guideline on 24-hour unit access for parents (or family designated substitutes) and infant- and family-centred developmental care.

Description

Early separation can affect maternal post-natal bonding (24), which in turn has been suggested to be a risk factor for the socio-emotional infant development. (25) Effects of early exposure to NICU stress may be at least partially alleviated by



developmental care practices. Parental presence, including the fostering of an early closeness between mother and newborn infant, has been shown to have short-term benefits for the infants. (10,15)

There are few studies that examine whether the actual amount of parental daily access is directly related to the effects seen for parental participation in care. Reynolds and colleagues examined parental access and parental holding of their infants in the NICU. Increased access was associated with generally better parameters of infant neurobehavioral functioning on the NICU Network Neurobehavioral Scale (NNNS) (26), while more holding was associated with improved quality of movement, less stress, less non-optimal arousal and less excitability of infants on the NNNS assessment. O'Brien and co-workers report higher rates of breastfeeding when the parents spend ≥ 8 hours per day in the NICU and participate in a Family Integrated Care model. (8)

When there is 24-hour access, parents have more opportunities to participate in various aspects of touching, holding, and caring for their infant and this participation in care will typically lead to beneficial effects for both the infant and family. However, 24-hour access does not necessarily assure that parents are participating actively in care of their infant. (2) Suggestions for supporting active, effective parental involvement in the care of their infant in the NICU will be addressed elsewhere.

Surveys of degree of parental participation in care and intervention studies which aim to study, and influence parental participation in care indicate a number of specific benefits (see benefits section). (6)

Infection risk management

In times of increased infections in the community, access for parents and extended family members is limited. A review of the literature related to epidemic nosocomial infection in neonatology proposes some preventing measures: (27)

- To limit the access of family members with on-going infection or who have been exposed to an infection recently
- To limit the duration and number of visits per week for siblings during the epidemic periods
- To vaccinate hospitalised infants and their relatives
- To wear protective masks, in the case of respiratory infection
- To reinforce hand hygiene measures

Ethical arguments

Beyond the increasing scientific evidence for the importance of parental presence with their infant in the NICU, there is an important human and spiritual consideration about the importance of early parent-infant contact for healthy human growth. And conversely, reduction of distress arising from separation of infant and parent is a moral imperative that goes beyond providing appropriate medical and nursing care for the infant. These considerations are addressed in the Humane Neonatal Care Initiative. (28)

Legal context

The United Nations Convention on the Rights of the Child indicates in the U. N. General Assembly Document A/RES/44/25 (12 December 1989)

- Article 7: The child ... shall have the right from birth to ... *be cared for by his or her parents*



- Article 9: States Parties shall ensure that *a child shall not be separated from his or her parents against their will ...*

In essence this is the right of the child to be with his or her parents at all times, including during periods of hospitalisation.

In the area of neonatal care, this means that not only providing adequate care to infants should be legally recognised in each country; but that healthcare institutions must provide ways for infants to be with their parent (family members) as a universally sanctioned legal right. The infant has a legal right, which should be provided for, by whatever means necessary, to be with their parent.

The European Association for Children in Hospital defines 10 Rights of Hospitalised Children in its Charter, Leiden, 1998 indicates:

- Point 2: a hospitalised child has the right to have both parents or their substitutes present day and night whatever his age or his medical condition.
- Point 3: we shall encourage the parents to remain with their infants and facilities should be offered to them with no extra cost to them or no loss in salary. Parents shall be informed about the rules and the operating conditions of the unit in order to let them actively participate in the care of their infants.

In some European countries national laws are available on the topic, for example:

France

- DH/E03/688 du 23/11/1998 specifies that whatever the situation, the mother, father or who cares for the infant must have access to the paediatric infant so long as the infant wishes them to stay
- HAS “Prise en charge de l’enfant et de l’adolescent 2011”- everything should be organised to allow parental access for hospitalised infants

Norway

- Forskrift om barns opphold i helseinstitusjon, Lov data Dato FOR-2000-12-01-1217

Portugal

- Lei n 106/2009 Hospitalisation Family Support- Portuguese Law

Spain

- Unidades de Neonatología. Estándares y Recomendaciones de calidad. Informes, estudios e investigación 2014. Ministerio de Sanidad, Servicios Sociales e Igualdad. NIPO: 680-14-147-2

Source

1. Casper C, Caeymaex L, Dicky O, Akrich M, Reynaud A, Bouvard C, et al. [Parental perception of their involvement in the care of their children in French neonatal units]. Arch Pediatr Organe Off Soc Francaise Pediatr. 2016 Sep;23(9):974–82.
2. Montiroso R, Fedeli C, Del Prete A, Calciolari G, Borgatti R, NEO-ACQUA Study Group. Maternal stress and depressive symptoms associated with quality of developmental care in 25 Italian Neonatal Intensive Care Units: a cross sectional observational study. Int J Nurs Stud. 2014 Jul;51(7):994–1002.



3. Greisen G, Mirante N, Haumont D, Pierrat V, Pallás-Alonso CR, Warren I, et al. Parents, siblings and grandparents in the Neonatal Intensive Care Unit. A survey of policies in eight European countries. *Acta Paediatr Oslo Nor* 1992. 2009 Nov;98(11):1744–50.
4. Latva R, Lehtonen L, Salmelin RK, Tamminen T. Visiting less than every day: a marker for later behavioral problems in Finnish preterm infants. *Arch Pediatr Adolesc Med*. 2004 Dec;158(12):1153–7.
5. Franck LS, Spencer C. Parent visiting and participation in infant caregiving activities in a neonatal unit. *Birth Berkeley Calif*. 2003 Mar;30(1):31–5.
6. Benzie KM, Magill-Evans JE, Hayden K, Ballantyne M. Key components of early intervention programs for preterm infants and their parents: a systematic review and meta-analysis. *BMC Pregnancy Childbirth*. 2013;13(Suppl 1):S10.
7. Browne JV, Talmi A. Family-based intervention to enhance infant-parent relationships in the neonatal intensive care unit. *J Pediatr Psychol*. 2005 Dec;30(8):667–77.
8. 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.
9. Raiskila S, Axelin A, Toome L, Caballero S, Tandberg BS, Montirosso R, et al. Parents' presence and parent-infant closeness in 11 neonatal intensive care units in six European countries vary between and within the countries. *Acta Paediatr*. 2017 Jun;106(6):878–88.
10. Ortenstrand A, Westrup B, Broström EB, Sarman I, Akerström S, Brune T, et al. The Stockholm Neonatal Family Centered Care Study: effects on length of stay and infant morbidity. *Pediatrics*. 2010 Feb;125(2):e278-285.
11. Meyer EC, Coll CT, Lester BM, Boukydis CF, McDonough SM, Oh W. Family-based intervention improves maternal psychological well-being and feeding interaction of preterm infants. *Pediatrics*. 1994 Feb;93(2):241–6.
12. Raiskila S, Axelin A, Rapeli S, Vasko I, Lehtonen L. Trends in care practices reflecting parental involvement in neonatal care. *Early Hum Dev*. 2014 Dec;90(12):863–7.
13. Mörelius E, Ortenstrand A, Theodorsson E, Frostell A. A randomised trial of continuous skin-to-skin contact after preterm birth and the effects on salivary cortisol, parental stress, depression, and breastfeeding. *Early Hum Dev*. 2015 Jan;91(1):63–70.
14. Reynolds LC, Duncan MM, Smith GC, Mathur A, Neil J, Inder T, et al. Parental presence and holding in the neonatal intensive care unit and associations with early neurobehavior. *J Perinatol Off J Calif Perinat Assoc*. 2013 Aug;33(8):636–41.
15. Montirosso R, Del Prete A, Bellù R, Tronick E, Borgatti R, Neonatal Adequate Care for Quality of Life (NEO-ACQUA) Study Group. Level of NICU quality of developmental care and neurobehavioral performance in very preterm infants. *Pediatrics*. 2012 May;129(5):e1129-1137.
16. Melnyk BM, Feinstein NF, Alpert-Gillis L, Fairbanks E, Crean HF, Sinkin RA, et al. 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 Nov;118(5):e1414-1427.
17. Melnyk BM, Feinstein NF. Reducing hospital expenditures with the COPE (Creating Opportunities for Parent Empowerment) program for parents and premature infants: an analysis of direct healthcare neonatal intensive care unit costs and savings. *Nurs Adm Q*. 2009 Mar;33(1):32–7.
18. Meyer, E., Lester, B., Boukydis, Z., Bigsby, R. Family-based intervention with high-risk infants and their families. *J Clin Psychol Med Settings*. 1998;5(1):49–69.



19. Melnyk BM, Crean HF, Feinstein NF, Fairbanks E. Maternal anxiety and depression after a premature infant's discharge from the neonatal intensive care unit: explanatory effects of the creating opportunities for parent empowerment program. *Nurs Res.* 2008 Dec;57(6):383–94.
20. Montirosso R, Provenzi L, Calciolari G, Borgatti R, NEO-ACQUA Study Group. Measuring maternal stress and perceived support in 25 Italian NICUs. *Acta Paediatr Oslo Nor* 1992. 2012 Feb;101(2):136–42.
21. Zelkowitz P, Feeley N, Shrier I, Stremler R, Westreich R, Dunkley D, et al. The Cues and Care Trial: a randomized controlled trial of an intervention to reduce maternal anxiety and improve developmental outcomes in very low birthweight infants. *BMC Pediatr.* 2008 Sep 26;8:38.
22. Zelkowitz P, Feeley N, Shrier I, Stremler R, Westreich R, Dunkley D, et al. The cues and care randomized controlled trial of a neonatal intensive care unit intervention: effects on maternal psychological distress and mother-infant interaction. *J Dev Behav Pediatr JDBP.* 2011 Oct;32(8):591–9.
23. UNICEF. The United Nations Convention on the Rights of the Child [Internet]. 1990. Available from: https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf?_ga=2.163550268.1218459234.1527076484-403558301.1527076484
24. Obeidat HM, Bond EA, Callister LC. The parental experience of having an infant in the newborn intensive care unit. *J Perinat Educ.* 2009;18(3):23–9.
25. Korja R, Latva R, Lehtonen L. The effects of preterm birth on mother-infant interaction and attachment during the infant's first two years. *Acta Obstet Gynecol Scand.* 2012 Feb;91(2):164–73.
26. Lester BM, Tronick EZ, Brazelton TB. The Neonatal Intensive Care Unit Network Neurobehavioral Scale procedures. *Pediatrics.* 2004 Mar;113(3 Pt 2):641–67.
27. Polin RA, Saiman L. Nosocomial Infections in the Neonatal Intensive Care Unit. *NeoReviews.* 2003 Mar 1;4(3):81e – 89.
28. Levin A. Humane Neonatal Care Initiative. *Acta Paediatr Oslo Nor* 1992. 1999 Apr;88(4):353–5.

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Lifecycle

5 years/next revision: 2023

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