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

Parental involvement

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Target group
Infants, parents of infants hospitalised in the neonatal intensive care units (NICUs) at all levels, and families

User group
Healthcare professionals, neonatal units, hospitals, and health services

Statement of standard
Parents are members of the caregiving team and, with individualised support, assume the primary role in the provision of care of their infant, and are active partners in decision-making processes.

Rationale
The goal is to ensure the parental involvement in the care of the infant. Most parents have a sensitive understanding of their newborn infant. Contingent with infant cues, parents normally and intuitively present well-timed interactions in multimodal forms involving the mediums of voice, proximity, touch and gestures to regulate infants' physiological, behavioural and emotional responses, and responding to their nutritional needs. (1) However, infants in neonatal intensive care units (NICUs) usually are physically and emotionally separated from their parents, making it difficult for the parents to assume this expected role of caregiver. (2)

Prematurity and illness imply infant fragility and behaviour quite different from that of healthy full-term infants, but implementing parent involvement can significantly improve the well-being of both parent and infant.

Although the majority of units in eight European countries reported a policy of encouraging both parents to participate in the care of their infants, the intensity and ways of involvement as well as the role played by parents varied within and between countries. (3) Parents are willing to practice new skills through guided participation, even for more complex care. (4) They experienced contrasted emotions during their first participation of care, with a prevalence of negative and ambivalent feelings, requiring the support of staff members to reach emotional resilience. (5)

Parental integration enables their participation in the medical discussions and decision-making about their infant. The full integration of families into the neonatal team to actively provide much of their infant's care is beneficial for both parents and the infants themselves.

Educational programmes can be established to involve parents in the care of their infant. They can have a more theoretical (6–8) or more practical (9,10) foundation. Care based on Newborn Individualized Developmental Care and Assessment Program (NIDCAP) (11) and other forms of integrated care models such as family integrated care (FICare) (1,2,6,8) or Close Collaboration with Parents (12,13), which in recent years have been implemented in different countries, enable parents to become active caregivers for their infant by participating as integral members of the care team. However, implemented programmes have to be adapted to the characteristics and resources of each unit.

Benefits

Short-term benefits

- Reduced length of NICU stay (10,14–18)
- Increased breastfeeding rate (3,16,19,20)
- Improved weight gain (3,16,19,20)
- Earlier achievement of enteral and suck feeds (18)
- Reduced occurrence of moderate to severe bronchopulmonary dysplasia (10)
- Reduced duration of supplemental oxygen (16)
- Lower rate of nosocomial infection (9,16,17)
- Lower antibiotic exposure (16)
- Lower need for parenteral nutrition, peripheral or central venous lines (17)
- Reduced stress and anxiety for parents (3,19,21,22)
- Increased understanding of and involvement in infant pain management (23)
- Increased satisfaction regarding communication about their infant (24)
- Reduced total medical expenditures (16)

Long-term benefits

- Reduced rate of readmissions (16,25)
- Increased breastfeeding rate at 18 months (16)
- Higher weight at 18 months (16)
- Reduced risk of maternal depression (22,25)
- Reduced maternal chronic stress (26)
- Improved child behaviour and long-term cognitive development (26–34)
- Improved quality of life for the child (27)
- Improved long-term outcomes from mother/father skin-to-skin contact (31)

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 their involvement in the provision of care for their infant during the stay on the neonatal unit. (16,19,26,34)	A (High quality) B (High quality)	Patient information sheet
2. Parents are the primary caregivers for their infant. (16,19,26,34,35)	A (High quality) B (Moderate quality) C (High quality)	Parent feedback
3. Parents participate in medical rounds. (3,6,7,10,16,19,26,34)	A (High quality) B (Moderate quality)	Parent feedback
4. Parents are partners in decision-making processes. (3,6,7,10,16,19,26,34)	A (High quality) B (Moderate quality)	Parent feedback
5. Parents have access to medical records. (3,19)	A (High quality) B (Moderate quality)	Guideline, parent feedback

For healthcare professionals		
6. A unit guideline on parental involvement in terms of being the primary caregivers, participation in medical rounds, and partnering in decision-making is adhered to by all healthcare professionals. (3,6,7,10,16,19,26,34)	A (Moderate quality) B (High quality)	Guideline
7. Training on integrating parents into the neonatal unit is attended by all responsible healthcare professionals. (3,7,9,10,14,16,19)	A (Moderate quality) B (High quality)	Training documentation
8. The role as educator, coach, and facilitator of care and bonding is undertaken. (3,7,9,10,14,19)	A (High quality) B (High quality)	Healthcare professional feedback
9. Support parental presence throughout the 24 hours. (3,6,7,10,16–21,26,34)	A (High quality) B (Moderate quality)	Guideline
10. Support specific father presence and participation in the NICU. (36–38)	A ((High quality) B (High quality)	Guideline
For neonatal unit		
11. A unit guideline on parental involvement in terms of being the primary caregivers, participation in medical rounds, and partnering in decision-making is available and regularly updated. (3,6,7,10,16,19)	B (High quality)	Guideline
12. A parent advisory panel is engaged in appropriate planning and decision-making processes. (3,9,10,14,16,19)	B (Moderate quality)	Parent feedback
13. Conduct ongoing quality assurance of parent participation. (3,6,7,16,19,26,34)	A (Moderate quality) B (Moderate quality)	Parent feedback
14. Provide a unit guideline for parental and family presence throughout the 24 hours. (3,6,7,16,19,26,34)	A (Moderate quality) B (Moderate quality)	Parent feedback
For hospital		
15. Training on integrating parents into the neonatal unit and resources for the parents as primary caregivers is ensured. (3,7,9,10,14,19)	A (High quality) B (High quality)	Training documentation
16. Appropriate resources are provided to support infant- and family-centred developmental care. (3,9,10,14,19)	A (High quality) B (High quality)	Audit report
17. Provide facilities for parents to reside in the neonatal unit (see NICU design). (3,10)	A (Moderate quality) B (Moderate quality)	Audit report

For health service		
18. A national guideline on the role of parents as primary caregivers of their infants and on the role of parents of advisory functions in hospitals is available and regularly updated. (3,9,10,14,19)	B (High quality)	Guideline

Where to go – further development of care

Further development	**Grading of evidence**
For parents and family	
• Parents give input to both written and electronic medical records. (3,10)	A (Moderate quality) B (Moderate quality)
For healthcare professionals	
• Consider and support the diversity among parents and families. (38)	A (Moderate quality) B (Moderate quality)
For neonatal unit	
• Provide unit guideline on full parental access and input to both written and electronic medical records by the parents. (3,6,7,10)	A (Moderate quality) B (Moderate quality)
For hospital	
• Include parents in hospital patient advisory committee. (3,6,7,10)	A (Moderate quality) B (Moderate quality)
• Be prepared to maintain the presence of parents in the NICU in exceptional situations (pandemic). (5,39–47)	A (High quality) B (High quality)
For health service	
• Be prepared to maintain the presence of parents in the NICU in exceptional situations (pandemic). (5,39–47)	A (High quality) B (High quality)

Getting started

Initial steps
For parents and family
• Parents are verbally informed by healthcare professionals about the importance of their involvement in the provision of care for their infant. (3,6,7,10,16,18–21,26,34,39)
• Parents are involved in daily care procedures, e.g. changing nappies, measuring temperature, hygiene of the mouth, bathing etc. (3,6,7,10,16,18–21,26,34,39)
For healthcare professionals
• Attend training on infant- and family-centred developmental care. (3,6,7,10,16,18–21,26,34,39)
• Welcome parents as active participants in the care. (3,6,7,10,16,18–21,26,34,39)
For neonatal unit
• Develop and implement a unit guideline on parental involvement in terms of being the primary caregivers, participation in medical rounds, and partnering in decision-making. (3,6,7,10,19)

- Develop information material on care and treatment of infants for parents. (16,19,26,34)

For hospital

- Support healthcare professionals to participate in training on infant- and family-centred developmental care. (3,6,7,10,16,18–21,26,34,39)

For health service

- Develop and implement a national guideline on family involvement in the care of their infant. (3,6,7,10)

Description

According to natural order, parents expect to be the primary caregiver of their newborn infant. Although the medical professionals in most neonatal units attempt to involve parents in the care of their infant it is generally accepted that the type of care required in the neonatal unit is highly complex and should therefore be a responsibility of experienced professionals. Inadvertently, this approach makes the parents feel like passive spectators regarding the care of their infant and tend to make them feel insecure, more stressed, anxious and less competent when they later take the infant home at discharge from the hospital. (48)

Despite the challenging circumstances, under the guidance and supervision of the healthcare professionals, the parents can gradually learn how to adjust the normal parent behaviour and carryout even the more complex tasks of caring for their infant. Subsequently – according to the individual competencies of the parents – the professionals will progressively be able to delegate most, if not all, nursing tasks to the parents.

Challenges associated with the involvement of the parents

It is possible that the parents may not detect changes that require prompt medical attention in their infant's condition. However, healthcare professionals retain primary responsibility for the infant and supervise parents closely, which should ensure that appropriate care is given. Another concern is that parents may become overly anxious about providing care for their sick infant. (5) However, the provision of care procedures by parents is introduced gradually and individualised according both to the situation of the infant and the parents. Most parents involved in these programmes report decreased anxiety and stress because they feel in control and well informed when given a purposeful role in the care of their infant. (9,26) Parents' involvement in the care of their newborn infants admitted to the NICU is beneficial to the newborn infant and the family. However, certain ethical aspects must be considered because otherwise families can be harmed. Parents cannot perceive that the care of their child is imposed on them. Professionals have to know how to adapt to the reality of each family and each NICU. Changes must be made progressively so that families can adapt. (49)

The role of fathers in the NICU

Most studies on the care of preterm infants are focused on mothers. In the first days of the newborn infant's admission to the NICU, fathers often play an important role if the mothers are with medical complications. However, soon the mother assumes the main role in the care of the infant and the father is relegated. (36) Interventions that involved mothers and fathers showed similar general positive effects in the infants with additional beneficial effects on paternal affective and mental health. Few

differential effects were seen between maternal and paternal interventions. (37) Therefore, professionals must provide the father with greater support to increase his presence and participation while his newborn infant is admitted to the NICU. This aspect is essential to achieve gender equality and promote co-parenting.

Lastly, diversity among parents and families should be considered. For example, not all parents are biologically related to their newborn infant, and families may include one or more parents, and parents of the same or different gender. Professionals must approach each of these particular situations with sensitivity, encouraging the family to become involved in the care of the newborn infant. (38)

The barriers to implementing the involvement of parents

For extremely ill infants who require mechanical ventilation or other complex treatments and where parents are not able to room-in, parental involvement in care giving is more challenging. Having parents as the primary caregivers in an intensive care setting represents a substantial shift in the current model of neonatal care in most countries. There are numerous barriers to widespread implementation of this model of care. Parents can feel stressed, over-whelmed and over-burdened when providing newborn infant care. (5,50) Thus, it is really important to give them continuous support and on an individual level, gradually introduce parents as the primary caregivers. On the other hand, healthcare professionals may feel uncomfortable about reducing their control of the infant's care. (51) Thus, also healthcare professionals could benefit from support and training concerning parental involvement. (3,6,7,10)

The involvement of parents in exceptional situations

The COVID-19 pandemic has highlighted the vulnerability of programmes that support parental involvement in the care of their newborn infants in the NICU. (39) In many cases, it has been difficult for more than one parent to be present and truly incorporated as members of the team caring for their newborn infant. (41) In some hospitals the father has not been able to care for his newborn infant in the NICU for several weeks. The restriction to fathers' access to the NICU acted as a significant obstacle to infant-father bonding and led to loneliness and isolation by the mothers. Thus, these COVID-19 measures might have had adverse consequences for infants and families. (42,44–47) It seems that when single family rooms were available, the restrictions were less important. (40) On the other hand, the stress and depression of the parents could be contained if the participation in the care of their newborn infants was maintained. (43)

In the face of new emergency situations, all necessary security measures must be taken, but always with the aim of keeping parents in the neonatal unit, supporting their role as caregivers. New technologies and the availability of single-family rooms can help ensure that restrictions, if they are essential, are as few as possible.

Source

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