Parental participation: essential for developmental care but challenging in neonatal wards

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Introduction

Premature babies, born at less than 37 weeks gestational age, represent 7% of births in Belgium. According to the degree of prematurity and severity of associated illnesses, the special needs of preterm infants are provided in neonatal units, ranging from non-intensive wards to high-tech neonatal intensive care units (NICUs). Despite progress in neonatal care, which have led to increased survival, premature infants are at risk of developing long-term morbidities such as complex cognitive dysfunctions, behavioural disabilities, and socio-emotional problems. These developmental morbidities do not only affect the most immature, but also moderately and late preterm infants born between 32 and 37 weeks of gestational age. To enhance neurobehavioral outcome, neonatal units try to implement developmental care policies. One of the key features of most developmental strategies is parental involvement and participation in the care of their baby. Yet, it remains one of the biggest challenges. It requires considering parents as primary caregivers and partners in clinical decision-making.

Principles of Family and Infant Centered Developmental Care (FICDC)

Throughout the hospitalization, preterm infants can be overwhelmed by lighting, noise, painful procedures, handling, and parental deprivation. Brain growth and establishment of neuronal networks occur during the NICU stay. Exposure to environmental stressors can have long-term neurodevelopmental repercussions. Parents of a preterm or a sick neonate, far from the joy of an expected normal pregnancy, very often live a stressful experience. Beside the fear of prematurity-associated comorbidities, the complexity of care delivered in neonatal units, requiring experienced professionals, can be very intimidating (1). The staff, who represents authority and expertise, can interfere with parents' perception of their child, and significantly alter their role (2). Consequently, parents may fear the proximity with their fragile babies and feel insecure or incompetent in providing them care and support (2). Sometimes, parental experience of stress is so unbearable that anxiety, depression or a post-traumatic stress disorder can arise, which can influence the relationship with the baby (3,4). This adversely impacted parent-infant relationship can be associated with poor long-term developmental outcomes, emotional instability, and child abuse (5).

Since the pioneering work of Heidelise Als in 1982, developmental care practices have been implemented in NICUs worldwide to decrease the stress in preterm and sick infants and promote their well-being, growth, and optimized neurological and behavioural outcome. They consist of a range of interventions including postural support, pain management, lactation and breastfeeding support, sleep protection, skin-to-skin contact (SSC), and observation of baby cues to favour individualization of care (6). Such strategies can only be successful if parents are fully recognized in their fundamental role and integrated in the decision-making process, funding the base for Family and Infant Centered Developmental Care (FICDC). This concept emerges from the evolution of the parental role in the last decades in neonatal wards. In the past, parents were considered as visitors having to respect limited visiting hours and without any active function in their baby's care. Today, most neonatal units adopt unrestricted parental access, promote SSC, and encourage participation in care and decision making. Albeit diverging in terms of theoretical concepts, the mainstay of all FICDC policies is welcoming parents and families in the neonatal units and actively involve them in the daily care of their baby (5). FICDC has short- and long-term benefits for the infant and the family (6). On top of technology in neonatal units, FICDC has also favoured survival and better integration of the fragile baby in the family (5).

Evolving to a FICDC unit requires fundamental changes in the daily approach to babies and their families. Parents are the constant in the child's life, whereas services and personnel fluctuate (1). The staff must emphasize the importance of parental presence for the short and long-term development of their child. As such, parents must be regarded as primary caregivers. Health care workers should involve them as partners in clinical decision-making. This implies a flexible staff that supports the crucial role of parents by bringing continuous assistance, adequate information, and individualized psychosocial support (6). Whilst parents involved in the treatment of their child feel more confident, health care professionals can have the feeling that parents interfere with their function. Therefore, FICDC policies must be clear and provide emotional and financial support to meet family and staff needs (1).

Benefits of parental participation

Physical and emotional closeness through sensorimotor interactions is crucial for the mother-infant bond, thereby helping regulate the infant's physiology and behaviour in the short term and its capacity to adapt in the future. Among different modalities of physical closeness, SSC, as a marker of parental participation, is medically safe and has the strongest evidence for a positive impact on the infant's health (7). Several clinical studies, mainly in the context of Kangaroo Care, compiled in meta-analyses including thousands of low-birth-weight infants have investigated the short- and long-term benefits

of SSC (7–9). As compared to conventional care, early and sustained SSC participates in the attenuation of pain during procedures, cardiorespiratory stability, and prevention of hypoglycaemia and hypothermia (8). At the time of discharge from the hospital, low-birth-weight infants are more likely exclusively breastfed and exhibit better growth profiles including head circumference (7,8). Moreover, SSC reduces the risk of sepsis and mortality in this fragile population, albeit the effect might be more pronounced in low-income countries (7,8).

Nurturing care interventions as Newborn Individualized Developmental Care and Assessment Program (NIDCAP) or continuous day and night family presence were also associated with a decreased risk of bronchopulmonary dysplasia and better general development in a Swedish setting (10,11). As a result, the possibility for parents to stay 24 hours a day decreased the length of NICU stay (11). Indeed, integration in the daily care of their baby may empower parents and favour their readiness for the transition from the NICU to home, thereby attenuating the financial impact of prematurity (3). The association between increased parental participation via SSC and improved outcomes needs further investigation but might involve combined effects of genome, epigenetics, microbiome, and anti-inflammatory properties of breastfeeding (11,12).

In addition, SSC is a moment belonging exclusively to parents, during which all neuroprotective care practices can be provided. SSC helps parents' sensitivity allowing a better understanding of the child's needs, bonding and later attachment between the parents and their baby. Parents also feel more confident and competent in parenting. Other benefits for the parents themselves include a decrease in stress, anxiety, and depression (13). A meta-analysis of 22 randomized controlled trials (RCTs) concluded that NICU interventions focused on FICDC seem to be the most promising ones in reducing parental stress (14). By contrast with the abundant literature assessing the benefits of parental participation for the mother-infant dyad, much less attention has been paid to fathers. They tend to be less present than mothers in neonatal wards, but they do not have to be considered as second level parent (15). Postpartum depression in fathers is a reality, with feelings of inadequacy and uselessness when compared to the maternal nursing role. Involvement of fathers in supporting breastfeeding may provide an opportunity to bond with their newborn. Their attitudes can influence mothers' breastfeeding decisions (16).

With regards to neurodevelopmental outcomes, SSC positively impacts developmental, cognitive, and emotional outcomes (17). While providing SCC, parents indeed promote the neurodevelopment of their baby by singing, reading to them, performing massages, protecting sleep, and preventing or reducing pain during procedures (8). Therefore, creating an environment that favours communication and minimizes distractions is meaningful (15). In a retrospective cohort study including about one hundred of extremely preterm infants, higher duration of SCC was associated with a better language score at 12 months, while cognitive scores remained unchanged (17). During the follow-up of an RCT comparing continuous SCC and standard care, prematurely born adults having benefited from SCC show better intellectual quotient scores, school performances, and social skills (18).

When results of RCTs were gathered in systematic reviews, the effectiveness of NICU interventions on neurodevelopment appears disappointing. Indeed, there is limited evidence supporting a positive effect of NIDCAP on behaviour and movement of preterm children at 5 years of age, with no significant effect on cognition (19). Another meta-analysis evaluating NIDCAP effectiveness on neurodevelopment failed to show significant benefits likely due to the lack of large, good quality trials (20). Overall, meta-analyses in the setting of developmental care might be difficult to interpret because of large variations in NICU interventions, limited number of RCTs, different target populations, precluding the identification of the most effective intervention (21). Beside differences between studies in terms of quality and inclusion criteria, this might also reflect the fact that parental participation, while being primordial for the infant's health, might not be enough *per se* to counteract all the detrimental effects of prematurity.

Barriers and facilitators to parental participation

Despite the benefits of parental participation, including parents in the everyday care remains a challenge for neonatal units. Identified obstacles to parental presence are numerous and strongly vary depending on geographical origin, as reflected by a prospective survey involving 11 NICUs across Europe (22). These differences might reflect variations in neonatal unit infrastructures, culture of care provided by the staff, hospital visiting policies, sociodemographic characteristics of parents and families, and social benefits offered in each country.

The infrastructure of neonatal units and policies of parental visits can strongly affect the participation and presence of families. With regards to FICDC, unrestricted access of parents to their baby is essential. Having access to a reclining chair or bed, a bathroom and kitchen can offer a better comfort and help parents stay around the clock (4). Having a place where the parents can gather and meet with family or friends can encourage them to spend more time in the unit.

Recent data have suggested that the presence of single rooms instead of an open-bay design could promote parental presence and contribute to their psychological well-being (23). Single rooms can be designed as family rooms, which allow the presence of siblings (4,22). Nevertheless, the existence of single rooms might increase maternal stress, which has been ascribed to a feeling of isolation and higher responsibility regarding the infant (24). The reason for these discrepancies between studies is unclear but might emphasize that other factors, such as the lack of adequate support from the staff and/or specific socio-demographic conditions, can overcome the benefits of staying in a single room.

The contribution of socio-demographic factors to parental participation is inconsistent in the literature (15). While the presence of siblings is a common limitation, other predictors of reduced parental participation have been highlighted such as the lack of income, long distance between the hospital and the residence, parent's health issue, and lower level of maternal education (16,22,24). In some instances, cultural and religious factors can be relevant to understand parents' and staff's reactions as gender assumptions and the presence of fathers (4). Another limiting factor for parental participation in neonatal wards is the infant's health condition and the degree of medical support provided. As such, more neonatal comorbidities and medical interventions correlate with less parental visits and duration of holding (24). This underlines the fact that high level of stress can make parents fear the proximity of their baby.

Because parental stress is a marker of parental involvement, addressing parents' psychological needs and supporting them emotionally during the hospital stay is critical to favour long-term bonding between infants and their families. Therefore, beside emotional, and empathic support, social workers and psychologists represent an added value to support family organization and/or provide financial assistance (4,5). Among social measures, the limited duration of paternity leave can explain, at least partially, the under participation of fathers (16). The length of paternity leave strongly varies from one country to another: it can only last a couple of days in some European regions, whereas it extends up to several months in Germany and Sweden. In countries providing longer paternity leave, fathers are more involved. Moreover, the perception that fathers have of their own function influences their participation during the hospital stay: the more they have the feeling that their presence is as essential as that of mothers, the more they will get involved in their baby's care (16).

Finally, as healthcare professionals have a role of educators, coaches and facilitators of care and bonding, their behaviour can significantly influence parental participation. On the one hand, the medical staff can be very intimidating for parents because they assert their authority and act to control the relationship in a protective attitude (1). On the other hand, for caregivers who are often highly stressed by monitoring and treatments, hour shifts, and the lack of available staff, the process of implementation of FICDC can be overwhelming. Moreover, depending on the infant's health status, the staff can fear or hesitate to propose parents to help for daily caregiving activities (25). The lack of experience and clear guidelines on developmental care measures makes implementation more complex. The efficacy of implementation can

vary greatly if the general policy in the neonatal unit establishes FICDC as a standard of care or a caring practice (25).

Involving parents and families in the practice: the starter pack

Considering principles of FICDC that have been integrated in paediatric care for the last decades, Table 1 summarizes concrete actions that can be implemented for children with special health needs, their families, and medical staff (1). Unlike older children hospitalized in a paediatric ward, the newborn admitted to the neonatal unit does not have time to fully integrate the family structure (1). Thus, the first contact in the neonatal ward can be very scary for parents. It is important to favour infant-parent interactions before explaining the medical condition and equipment (5). Parents must be involved progressively, without forcing them. The staff should privilege this first contact, making a positive moment to help build a secure emotional relationship. More than just hands-on care, the staff should coach parents based on respect and dignity, information sharing, participation, and collaboration. Parents must be informed about the importance of their presence and involvement in the provision of care. This implies that the NICU staff should be trained and properly informed on neuroprotective developmental care for preterm infants and the importance of family. For such unit changes to occur, creating guidelines is essential (4). Having a unit policy on parents and family involvement, to which all the staff adheres, is an important tool to promote the implementation of FICDC. Coaching and training parents can represent a considerable time investment for the staff at the beginning. Yet, as parents become more confident and increasingly involved in caregiving and feeding of their baby overtime, the workload of the nursing staff decreases (3).

Regular and clear communication between parents and staff is a corner stone to change from a system-centered where rules are imposed, to a FICDC approach that provides families the possibility to determine what works best for them (4). Because the information can be difficult to understand, especially the first days after birth, it must be repeated, consistent and clear (26). Having a limited number of reference staff as a care team for the infant can favour collaboration and make the parents feel as equals and partners. Their active participation in medical rounds improves communication, enhances collaboration with the medical team, and increases satisfaction. When parents feel recognized as partners and not simple visitors, they feel supported and have a sense of control over the situation (16). When parents and all the members of the multidisciplinary team find their place in the continuity of FICDC, satisfaction increases for families and the NICU staff. Finally, parent-to-parent support is often highly appreciated and might be beneficial for implementation and perpetuation of FICDC.

Since space and privacy can influence parent-infant closeness (27), NICU infrastructures are often presented as a limiting factor for the implementation of FICDC. However, the Group of Reflection and Evaluation of the Environment of Newborn with the French Society of Neonatology (GREEN) and the French parents' associations concluded that the sensory content of the environment might be more meaningful than the design of the ward (28). Single rooms offer many benefits but are not always the solution for families or staff because they offer privacy but are also a source of isolation (29). In a meta-analysis including 1850 preterm infants, no differences were observed regarding anxiety, infant-parent bonding or self-efficacy between open bay units or single-family rooms, even if there are other benefits as higher parental presence, higher rates of breastfeeding, and lower rates of sepsis (30). Anyways, in many infrastructures moving to a single-family room unit is often unrealistic. Alternatively, inexpensive adaptations for open bay units can be suggested to facilitate parental presence by providing a specific place with folding screens, comfortable chairs, and/or beds allowing an overnight access. Nonetheless, the negotiation of space and place can be very challenging in open bay units and acknowledging the ownership of a place gives the feeling of being respected as a primary caregiver (26,27). Efforts to create a calm atmosphere are also essential since parents as infants can be overwhelmed by the light and noise in the unit (26).

When considering FICDC, family is far broader than just the parents. Siblings should not be forgotten. They can feel neglected since their parents spend a long time in the neonatal unit. They must be informed, and be able to

Table 1: Summary of elements to facilitate the implementation of family-centered care.

Principles of family-centered care	Concrete actions
Sustained family-infant relationship	· Unrestricted access · Specific and comfortable place nearby the infant · Welcoming siblings and other family members
Parent-professional collaboration	· Regular and clear communication · Partnership relation · Staff as facilitator of bonding
Support family strength and individuality	· Individualized care · Respect cultural and social diversities · Enhance parent and infant competences · Give parents a sense of control
Sharing information on an ongoing basis	· Parent enrolment in medical rounds · Recognize parents as partners
Parent peer support	· Create a parent advisory board · Work with parent associations · Parent groups
Understanding and incorporating developmental needs	· Staff training on age-appropriate care · and risks of inappropriate stimulations · Parent coaching · Acknowledge the benefits of parental presence
Emotional and financial support for families	· Unit psychologist and social worker · Activities for siblings · Catering / parking facilities / transport facilities
Flexible, accessible, and responsive health care for families	· Clarify parents and staff roles and expectations · Attention to power relationships · between parents, nurses, and physicians · Ask families what is important for them
Implementing policies and programs to provide support for the staff	· Considering FICDC as a standard of care · Allow investments for infrastructure and staff · Clear guidelines and staff training

visit, and participate according to their age and personality. Parents of a hospitalized newborn can decide who they consider as family members. Hence, grandparents, other family members, or close friends can be crucial resources for psychological support and precious logistical assistance.

Several programs and resources supporting the implementation of FICDC are available. For example, the 'Family and Infant Neurodevelopmental Education program®' or the 'Close Collaboration with Parents Training Program®' have been created to guide neonatal units and caregivers in establishing this collaboration. The European Foundation for the Care of Newborn Infants (EFCNI) has recently published standards of care for newborn health and emphasizes the primary role of parents in the provision of care (https://www.efcni.org/). They state that: (i) parents must have unrestricted access to the neonatal ward; (ii) continuous SSC should be promoted; (iii) family needs should be recognized and supported; and (iv) a parental advisory board can help implement FICDC.

Conclusion

Integrating parents in the care of their newborn optimizes developmental protective measures. Parents learn to read their infants' cues and are a warranty for the individualization of care. Parental involvement, combined with a respectful and thorough communication that favours a partnership with the NICU staff, allows an increased general satisfaction. However, evaluating the effects of these interventions in clinical studies remains difficult. In the future, the development of standardized outcome sets evaluating FICDC interventions would be useful to determine the most adapted ones and allow better quality large trials (9). Finally, the one-size-fits-all approach cannot be given for FICDC. Each neonatal unit should identify its own barriers and enablers including physical environment, healthcare worker beliefs, clinical practice, and characteristics of parental presence. Adherence to local guidelines and search for creative solutions for space and unit design are needed to boost a change in practice.

Conflict of interest

The authors have no conflict of interest to declare with regard to the subject discussed in this manuscript.

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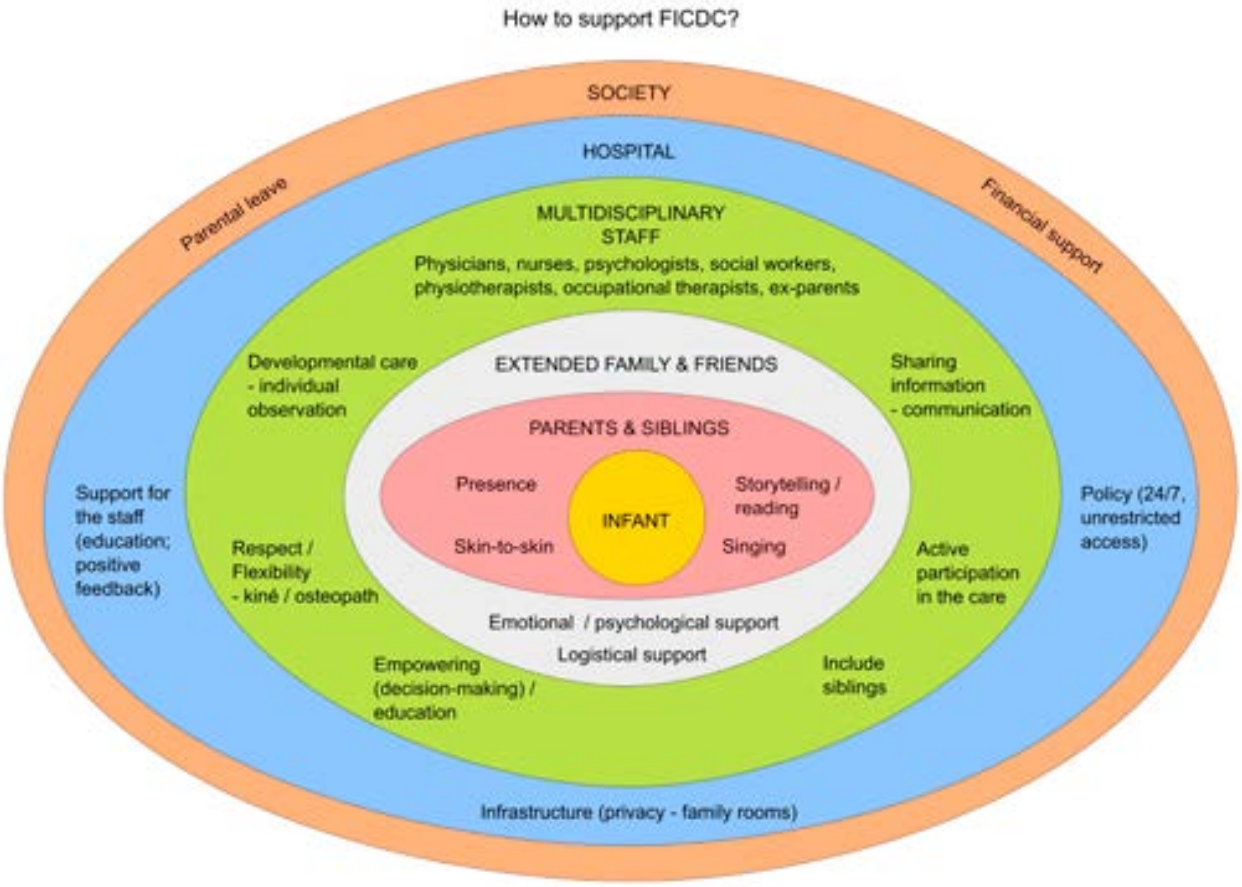
Figure



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