

## REVIEW

## Recommendations for involving the family in developmental care of the NICU baby

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Family involvement is a key to realize the potential for long-lasting positive effects on physical, cognitive and psychosocial development of all babies, including those in the neonatal intensive care unit (NICU). Family-centered developmental care (FCDC) recognizes the family as vital members of the NICU health-care team. As such, families are integrated into decision-making processes and are collaborators in their baby's care. Through standardized use of FCDC principles in the NICU, a foundation is constructed to enhance the family's lifelong relationship with their child and optimize development of the baby. Recommendations are made for supporting parental roles as caregivers of their babies in the NICU, supporting NICU staff participation in FCDC and creating NICU policies that support this type of care. These recommendations are designed to meet the basic human needs of all babies, the special needs of hospitalized babies and the needs of families who are coping with the crisis of having a baby in the NICU.

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## BACKGROUND

The provision of family-centered care has been endorsed by the American Academy of Pediatrics and many other health-care organizations.<sup>1</sup> However, gaps have been demonstrated between the goals of family-centered care and its actual practice.<sup>2–4</sup> Family-centered developmental care (FCDC) takes family-centered care one step further by involving the family as an essential contributor to the provision of individualized, developmentally supportive care of their baby.<sup>5</sup> FCDC provides the strong supportive foundation families in the neonatal intensive care unit (NICU) need to optimize the lifelong relationship between themselves and their babies, as well as to optimize the baby's physical, cognitive and psychosocial development. Embracing families as decision-making partners and collaborators in their baby's care has long been recognized as an optimal way of caring for babies in the NICU. A primary goal of FCDC is to minimize the lasting negative effects that a baby's illness may have on parent–baby interactions.<sup>6</sup> Reaching this goal can be accomplished through identification of individual infant/family vulnerabilities and strengths<sup>7</sup> and then finding ways to address these characteristics in the antepartum period, continuing through NICU admission, and on to NICU discharge and the transition home.

Fully implementing FCDC requires a global change in culture<sup>8</sup> and in the behavior of the many professional disciplines working within the NICU, and FCDC demands an expansion of the historic role of the NICU health-care team.<sup>9</sup> One way for NICU teams to develop and expand their FCDC practices is through the implementation of quality improvement initiatives.<sup>2</sup> This article presents key areas that these initiatives should address: (a) parent support, (b) staff support and (c) NICU policies.

The following recommendations for developmentally supportive care are critical components of standard medical care providing for the basic human needs of all babies. The

recommendations address the special needs of babies who are admitted to the NICU as well as the needs of families who are coping with the crisis of having a baby in the NICU.

## SUPPORTING PARENTS' ROLES AS CAREGIVERS OF THEIR BABIES IN THE NICU

Historically, the model of care for the NICU baby included almost complete separation from the mother and the family, with the baby enveloped in technology and cared for by highly trained personnel.<sup>9,10</sup> After the baby was 'cured and ready for discharge' the family was notified to take their baby to home. While separation of babies from mothers has a profound negative effect on the baby's physiologic stability, as well as psychosocial well-being and brain development, the current model of care for the NICU acknowledges that the effects of a premature birth or hospitalization of a sick newborn are not only experienced by babies but also by parents and families. This separation is especially true for very low birth weight babies and their families, as these babies spend significant time away from their parents and are at high risk for long-term developmental and behavioral problems.<sup>11,12</sup> Parents of premature babies often lack support and opportunities to engage in parenting while in the NICU, leading to frequent misperceptions of their baby's behavioral cues<sup>13</sup> and even labeling of their babies as 'difficult'.<sup>14</sup> The separation of parents from their baby in the NICU<sup>15</sup> combined with parental mental health issues such as depression, post-traumatic stress disorder, anxiety and other stress-related conditions can adversely affect the parent–baby relationship resulting in adverse outcomes for the baby's social and emotional development,<sup>16,17</sup> and behavioral<sup>18</sup> and cognitive functioning.<sup>19,20</sup> This separation may render the preterm baby, especially one who is very low birth weight, to be at risk for abuse and maltreatment following hospital discharge.<sup>17,21,22</sup>

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Parents of premature and sick babies must develop and maintain an appropriate understanding of their babies' needs in order to be prepared for home caregiving.<sup>11,23</sup> Studies by O'Brien *et al.*<sup>24</sup> in Canada and Ortenstrand *et al.*<sup>25</sup> in Sweden, in which families were fully integrated into the NICU team and actively provided much of their babies' care, showed many benefits to both parents and babies. Mothers had lower stress scores and felt more knowledgeable and confident, while babies had improved weight gain and a higher rate of exclusive breastfeeding at discharge in the O'Brien *et al.*<sup>24</sup> trial. The length of stay was shorter for babies in the Ortenstrand *et al.*<sup>25</sup> trial. Phillips *et al.*<sup>26</sup> found that supporting mothers in the NICU to respond to their babies' behavior in an effort to support attachment led to significantly higher rates of breastfeeding at 8 weeks after birth.<sup>26</sup>

Several studies have revealed a link between infant stress in the NICU and the corresponding changes in brain architecture. Smith *et al.*<sup>27</sup> demonstrated that when neonates were exposed to increasing numbers of stressors in the NICU, the babies had regional alterations in brain structure and function, as determined by magnetic resonance imaging, as well as abnormalities in motor behavior on neurobehavioral examination. However, when parents of premature babies are shown how to recognize their baby's behavioral, social and physical cues, parents facilitate their baby's developmental and physical progress, further reflected by changes in the brain's structure. Milgrom *et al.*<sup>28</sup> found that when parents participated in a 10-session training program to help them reduce their preterm babies' stressful experiences, their babies' brains showed improved cerebral white matter micro-structural development, again as determined by magnetic resonance imaging. In another study, preterm babies who received 8 weeks of skin-to-skin contact with their mothers demonstrated accelerated functional brain maturation as assessed by electroencephalogram, when compared with babies who did not receive such contact.<sup>29</sup>

Further work by Milgrom *et al.*<sup>30</sup> evaluated the impact of an extended intervention using the enhanced Mother-Infant Transaction Program, called PremieStart, on both mothers and their babies born at < 30 weeks gestation. The goals for mothers who participated in this training were to recognize and minimize stress responses in their babies. Mothers who participated were found to be more sensitive to their babies and were appropriately responsive to the identified stress behaviors. Their babies displayed fewer stress behaviors at term equivalent age and showed more advanced communication development at 6 months corrected age. This latter finding gives promise that the intervention may provide an early benefit to cognitive and pre-linguistic development. White-Traut *et al.*<sup>31</sup> demonstrated that when mothers received information on how to provide their babies with simple, developmentally appropriate multi-sensory stimulation through the 'Hospital to Home Transition—Optimizing Premature Infant's Environment' program, their babies had better weight gain during the hospital stay and were less likely to see a health-care provider for an illness in the 6-weeks post-NICU discharge.<sup>32</sup> Parents also benefited when they were supported to improve interactions with their babies. Melnyk *et al.*<sup>13</sup> found that parents who participated in the 'Creating Opportunities for Parent Empowerment' program during their NICU stay reported less stress while in the NICU and less depression and anxiety at 2 months' corrected infant age than did mothers who did not receive the intervention. Babies of participating mothers also had a shorter length of stay in the NICU.<sup>13</sup>

Taken together, these studies provide a strong basis for interventions that support parents in the parenting role and guide parents in developmentally appropriate interactions with their preterm and sick babies. These interventions have the potential to lessen the adverse impact of environmental stressors to which NICU babies are exposed, ultimately lessening the chance of poor developmental outcomes. In addition, positive benefits of reduced

stress and improved parent mental health outcomes ultimately can further improve parents' relationships with their babies.

Recommendations for supporting parents' roles as caregivers of their babies in the NICU:

1. Parents should be incorporated as full participatory, essential, healing partners within the NICU caregiving team. As partners within the medical team, parents should:
  - (a) Assume the parental role through provision of hands-on care to their baby including early, frequent and prolonged skin-to-skin contact as is medically appropriate, with coaching, guidance and support from the NICU staff;<sup>33</sup>
  - (b) Participate in both medical rounds and nursing shift change reports;<sup>1,34</sup>
  - (c) Honor both Health Insurance Portability and Accountability Act (HIPPA) and safety concerns while in the NICU; and
  - (d) Have full access and input to both written and electronic medical records.
  
2. Parents and family members should be supported to engage in developmentally appropriate care in order to become competent caregivers and advocates for the neuroprotection of their babies.<sup>13,14,35</sup> Components of parent support should include guidance on how to:
  - (a) Provide comfort and security through consistency of their presence for their baby whenever possible;
  - (b) Understand the behavioral communication of their baby so as to best interpret and respond to the baby's needs;
  - (c) Create and sustain a healing environment with respect to sensory exposures and experiences;
  - (d) Provide supportive positioning and handling for their baby, including supportive oral feeding experiences, skin-to-skin contact (kangaroo care) and infant touch;
  - (e) Collaborate with NICU staff to minimize their baby's stress and pain in the developmentally-unexpected environment of the NICU;
  - (f) Safeguard their baby's sleep, recognizing the importance of sleep to healing, growth and brain development;
  - (g) Optimize their baby's nutrition with breast milk and breastfeeding whenever possible; and
  - (h) Protect their baby's skin and its many functions, including its role as a conduit of neurosensory information to the brain.

#### STAFF PARTICIPATION IN FCDC

Commitment by leadership throughout the health-care system to an interdisciplinary model of care is essential for successful implementation of FCDC in the NICU, including administration, medical and nursing teams, and all other hospital staff who provide supports and services to babies and families in the NICU.<sup>3</sup> The needs of babies, families and staff are better met with an integrated team approach to achieve optimal outcomes.

Recommendations for staff participation in FCDC:

1. A culturally appropriate and warm welcome for families should accompany the admission of each NICU baby. Basic introductory resources written in the primary language should be provided and continued throughout their NICU stay. When parents are able to be with their baby, the following should be reviewed with them: hand hygiene practices, staff roles and simple explanations of equipment. However, *before* medical equipment is explained, the focus should be on promoting baby-parent interaction. Emphasis should be placed on the critical importance of the parents' presence to the short- and long-term outcomes of their babies, and parents should be

- assured of unlimited, around-the-clock information and access to their baby.
2. Staff should be educated on principles and methods of implementing FCDC, including the above topics in 'supporting parents' roles' #2.<sup>3</sup>
  3. Staff communications with parents and families should be regular, understandable (free of medical jargon), personalized, consistent and carried out in a culturally proficient manner.<sup>36</sup> The quality of staff communication with parents and families, as provided by every member of the care team, is a key to ensure success of FCDC.

### NICU POLICIES TO SUPPORT FCDC

Because of advances in medical technology, the survival rates of sick and premature babies have greatly increased.<sup>37</sup> Moving beyond mere survival, the focus of FCDC is on quality of life, neuroprotection and successful integration of the vulnerable baby into a healthy family unit.<sup>35</sup> This requires integrated relational care, which must begin at delivery or as early as possible during the antepartum period.<sup>38</sup> A team of professionals trained in the developmental support of the parent–baby dyad, such as infant developmental specialists, specially trained nurses, doctors and psychologists, along with neonatal therapists including occupational therapists (OT), physical therapists (PT) and speech language pathologists (SLP) must be involved in delivering this care as part of an interdisciplinary team.<sup>11,39–41</sup> Using an integrated, neuroprotective, family-centered, developmental care model, specially trained neonatal therapists should provide individualized therapeutic interventions in the NICU.<sup>41</sup> Attention to the experience of the baby and family requires a system-wide approach,<sup>2</sup> and the inclusion of multiple disciplines as a standard of care.

Recommendations for NICU policy to support FCDC:

1. A policy of unlimited, open access for parents should ensure around-the-clock information and access to their baby, including medical rounds and nursing shift changes. Parents should not be viewed or referred to as 'visitors', but rather part of the care team.
2. Clear policies and procedures should promote the participation of parents' support system; including the baby's siblings, grandparents, extended family and parents' friends, recognizing the importance of their involvement to the family's well-being.<sup>19,42</sup>
3. Support to the family should begin whenever maternal or fetal conditions and diagnoses are identified that could lead to an NICU stay. This support should include an antenatal consultation with the NICU health-care team, including the developmental specialist or neonatal therapists (OT, PT and SLP),<sup>11,39–41</sup> as well as an anticipatory lactation consultation.
4. Optimal family support in the NICU should include provision of:
  - (a) Tangible resources; such as a family lounge, sleeping rooms, showers, laundry, kitchen, computers and a family room in which to practice caring for the baby before discharge. Learning materials about infant development and care practices should be created in understandable language and provided in either written or digital form (in the form of videos or apps), as parents may desire;
  - (b) Psychosocial support for parents from every professional group providing care in the NICU including the neonatologists, nurse practitioners and nurses, social workers, psychologists, neonatal therapists/developmental specialists (OT, PT and SLP), lactation consultants, hospital chaplains and the palliative care team;<sup>41</sup>
  - (c) Expanded family support inclusive of grandparents and siblings, as well as childcare while parents are caring for their baby in the NICU;<sup>42</sup>

- (d) Peer-to-peer support<sup>1</sup> (see also 'Recommendations for peer-to-peer support for NICU parents', this issue); and
  - (e) Referrals to resources within the community; such as mental health services, smoking cessation resources and services for parents who may have inadequate housing, transportation, food or clothing, as facilitated by the perinatal social worker or other staff members.<sup>43</sup>
5. In the case of a baby's death, an interdisciplinary palliative care and bereavement team should provide services to support the baby's parents and extended family (see 'Recommendations for palliative and bereavement care in the NICU: a family-centered integrative approach', this issue).
  6. Preparing for the transition from the NICU to home should begin at the time of the baby's admission (see 'NICU discharge planning and beyond: recommendations for parent psychosocial support', this issue). Parents should be provided with:
    - (a) Anticipatory guidance and education about criteria for discharge;
    - (b) Education about Back-to-Sleep and Shaken Baby Syndrome and other issues related to baby's safety;
    - (c) Opportunities to develop competence and self-efficacy in the care practices needed for their baby at home;
    - (d) Follow-up resources including referral appointments to appropriate care providers, which may include home nursing visits, developmental care specialists (OT, PT and SLP) and breastfeeding support; and
    - (e) An assessment of their social support system, their risk for postpartum depression or other emotional distress<sup>44</sup> and the safety of their home environment as needed.
  7. Quality improvement projects on FCDC should become an integral part of the care provided.<sup>2</sup>
  8. Hospital committee structure and NICU policy development should include family advocates as regular members.

### SUMMARY

The transformation envisioned in the family-centered, developmentally supportive model of care incorporates the family fundamentally and consistently into the care of their baby, recognizing parents as important collaborative members of the NICU team<sup>1,11,45</sup> and embracing their roles as facilitators of their baby's development. Family involvement is a key to realize the potential for long-lasting positive effects on their baby's physical, cognitive and psychosocial development. It is imperative that NICU policies for parent support and staff support for FCDC be in place to offer the standard of care necessary for optimal outcomes of both baby and parent. Parent support should begin as soon as maternal or fetal concerns are identified that could lead to an NICU stay. Incorporating parents as full participants in their babies' care should include provision of information regarding (a) developmental care principles and (b) infant-communicated behaviors indicating stress and/or stability. Staff should be educated on principles and methods of implementing FCDC. Additionally, NICU policies and procedures should support the participation of parents as part of an interdisciplinary team. Finally, hospital committee structure and NICU policy development should include family advocates as regular members. Quality improvement projects on FCDC should become an integral part of the care provided.

### CONFLICT OF INTEREST

SL Hall has a consulting agreement with the Wellness Network, but this organization had no input or editing rights to the content included in the guidelines. The remaining authors declare no conflict of interest.

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