Neonatal family-centered care: evidences and practice models

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ABSTRACT

Although advances in neonatology have reduced the mortality rate of high-risk infants, sick newborns or premature infants have been exposed to more intensive monitoring and painful procedures, and lengthy hospitalization leading to prolonged separation from their parents. Over recent decades, the importance of parent-infant closeness early in an infant’s life has become more apparent, especially for preterm infants who are prone to neurodevelopmental deficits. There is an increasing body of evidence on the benefits of family-centered care (FCC) in the neonatal intensive care units. Key aspects related to neonatal FCC include parents’ presence in the ward, and their participation in the infant’s daily care and decision-making. In addition, the environment that supports a private and comfort space for each family member and infant, such as a single family room, should be provided. To successfully implement FCC in neonatal intensive care units, the culture of care and hospital policies should be changed, and appropriate training for medical staff is also required.

Keywords: family-centered nursing, newborn infant, neonatal intensive care unit, private room
KEY MESSAGE

- Concrete evidences exist about importance of early attachment between parents and their infant, and how to support it through family-centered care (FCC) in the neonatal intensive care unit.

- Key components of FCC are the parents’ presence, and their participation in the infant’s care and decision-making.

- A private and comfortable space should be provided next to the incubator. A single family room is ideal, however, a quiet space with a recliner separated by curtains can be a good alternative place to start FCC.

- Changing of the care culture and training for medical staff are required.
Family-centered care in NICU
It supports the parent-infant attachment, parental presence and active participation in the daily care and decision-making.
INTRODUCTION

A great amount of knowledge already exists on the importance of early attachment between the parent and infant and how to support it through family-centered care (FCC) in the neonatal intensive care unit (NICU).\textsuperscript{1-4}) Non-separation of infant and parents has ethical and legal support by the United Nations Convention on the Rights of the Child from 1989, which states ‘The child … shall have the right from birth to … be cared for by his or her parents’ in Article 7 and ‘Parties shall ensure that a child shall not be separated from his or her parents against their will’ in Article 9.\textsuperscript{5}) The American Academy of Pediatrics has adopted a list of recommendations to emphasize FCC since 2003\textsuperscript{6}) and has extended the responsibilities of the health care professionals to ensure implementation of FCC in their practice since 2012 (Table 1).\textsuperscript{7}) According to the European Association for Children in Hospital charter, ‘Children and young people in hospitals and other healthcare services shall have the right to have their parents or parent substitutes with them anytime, anywhere, any place, 24-hours a day, regardless of the age of the child or young person’ in Article 2.\textsuperscript{8}) However, few NICUs in Korea put the FCC policy in their daily practice.

FCC is a philosophy or a paradigm of care that is defined as comprehensive and holistic care of patients and their families, with emphasis on family participation, respect for families’ preferences, needs, and differences, and transparent communication and knowledge sharing.\textsuperscript{9}) Respect to the high-risk infant hospitalization, the development of FCC models has gone a long way toward supporting the parent-infant closeness during the past 40 years, and in which the hospital care for infants was executed in mutual relationship with parents. The present review summarizes the evidences supporting FCC and practice models promoting implementation of FCC in NICUs.
PARENT-INFANT CLOSENESS

Neurobiology of parent-infant closeness

The primary function of early caregiver recognition and attachment is to ensure the closeness and, resulting in the survival of a newborn infant. The newly born infants undergo a burst of norepinephrine during the birth process that leads to learn their mother’s odor and to approach their mothers. Besides that, many hormonal and neurotransmitter mechanisms have developed to draw parents and their babies into close proximity and emotional closeness with each other. Therefore, disturbances of these regulation may lead to various effects on the infant’s cognitive and emotional development. Also, nurtured attachment from parents play as an important role in the infant’s stress regulation.

Oxytocin is a most well-known hormone as an important transmitter in the process of formation close relationship between the mother and the infant. A great amount of oxytocin is secreted in pulsatile releases at birth. The mother’s closeness and caring actions after birth increase this pulsatile secretion of oxytocin. Oxytocin is known to enhance the function of the hypothalamus-pituitary-adrenal axis to regulate the infant’s fear and stress behavior. Early sensory functions affect which part of the brain undergoes enhancement of the oxytocin ‘pathway’ and how the brain reacts in human interaction later in life.

Another famous neurotransmitter engaged in fundamental bonding is dopamine. Dopamine-producing neurons are close to oxytocin receptor neurons in striatum and ventral tegmentum, enabling the oxytocin bursts produced by closeness and caretaking actions to activate the brain’s reward processes. Through complicated neural networks and integration
mechanisms, both oxytocin and dopamine system participate and carry out many different actions and influences including neuromodulation of social behavior, stress regulation, and associative learning.\textsuperscript{14–16}

\textit{Developing brain of an infant}

During the third trimester, the fetal brain grows 4-fold and this accompanies marked increase of brain surface area, resulting the emergence of sulci and gyri.\textsuperscript{17} While significant changes occur in a very short time period, a largely number of neuronal connections are developed by the mid-gestation and the environmental factors are essential in this development.\textsuperscript{17,18} The most important neural pathways are the thalamocortical and corticothalamic pathways involved in sensorimotor information.\textsuperscript{18} Thalamocortical pathways relay sensory and motor information from sensory receptors in the body through the thalamus to the sensorimotor area of the neocortex; the corticothalamic pathway transmits information generated in the cortex back to the thalamus.\textsuperscript{17,18} Because these essential pathways are developed from the 26 weeks of gestation,\textsuperscript{18} preterm infants are at high risk for motor, cognitive and behavioral deficits that become evident in childhood.\textsuperscript{19}

The NICU environment exposed to preterm infants, including bright lights, high levels of noise, and frequent noxious interventions, may have detrimental effects on the immature brain and alter its subsequent development.\textsuperscript{20,21} Imaging studies reported that preterm infants have smaller cortical surface area, lower volumes of grey matter, white matter, basal ganglia and cerebellum than term infants.\textsuperscript{22–24} One functional MRI study showed that the most affected brain area in the premature infants were short-range connections in frontal, parietal...
and occipital regions, which are linked to cognitive efficiency, social cognition, emotion and language development.19)

The earliest noted fetal sensory response is the movement of extremities, head or mouth or changes of heart rates to the external stimulation by 21 to 23 weeks of gestation.25) This early development of tactile sense offers a good reason to suggest that skin-to-skin contact (SSC) as an important element of parent-infant closeness for preterm infants during NICU hospitalization. Also, taste is known to be already developed in 16 to 18 weeks of gestation and olfactory sense between 28 to 32 weeks.26,27) SSC is now a proven primary recommended care practice that has been shown to have clear positive effects for both parents and infants.3,28) And, of course, a parent’s presence is a prerequisite for SSC and any other forms of physical parent-infant closeness.

PARENT PARTICIPATION IN THE INFANT CARE

Family-centered care and parent’s role

The first primitive model of FCC and its effectiveness in the care of preterm infants was introduced in the mid-1980s from the area suffered from shortages of medical staff and equipment.29,30) As increasing amount of reports on the positive effects of physical closeness between parents and infants, many western countries had started to loosen the visitation restrictions for parents from late-1990s to early-2000s.31) And parent’s presence can be supported by creating a meaningful role for them in the care of their infant during hospitalization.32) Nowadays, in most western countries’ NICUs, parents actively take care of their infant by providing SCC, taking parts in their infant’s pain management, managing the daily care routines of the infant, and participating in medical decision-making, therefore
becoming an important part of the care team.\textsuperscript{33,34})

The term of FCC has been used to represent various models of care that are family focused and partnered. The components of a neonatal FCC model are not precisely defined, presenting a challenge when evaluating the research on FCC.\textsuperscript{35}) A fundamental aspect of FCC in the NICU context is that the infant should never be cared for without considering the whole family and partnership with the parents. Families are acknowledged to be integral members of the care team and are considered to be primary decision makers for their infants.\textsuperscript{36}) In 2005, the European Science Foundation suggested eight principles for neonatal FCC (Table 2) and a more recent study announced that implementation of these principles do not require additional research due to the concrete body of evidence.\textsuperscript{37})

Beyond understanding the principles of care, implementing the knowledge on FCC to the everyday practice and guiding parents to participate in the neonatal care are challenging processes. There have been many different FCC intervention models developed, studied and have shown benefits for infants’ development (Table 3). The Infant Behavioral Assessment and Intervention Program (IBAIP), Mother Infant Transaction Program (MITP) and Parent Baby Interaction Program (PBIP) aimed to help parents to interpret the behavioral cues and sensitize parents to the way in which their infant handles environmental information to enhance confident and co-regulatory interaction with their infants.\textsuperscript{4,38,39}) Guided Participation (GP), Creating Opportunities for Parent Empowerment (COPE) and Positive Parenting Program (Triple P) are supporting parents to interpret their infants and to enhance their parenting capacity.\textsuperscript{40–42}) By using standardized information material, the parents become to be prepared and learn about behavior, reactions and are informed on how they can support infants in these situations. Family Nurture Intervention (FNI) and Family Integrated Care
(FICare) focused to integrate parents and family members as partners in the infant’s care, so they are included in providing daily calming, nurturing and interaction activities in NICUs.\textsuperscript{43,44} Most recently, one Swedish group developed Early Collaborative Intervention (EACI) program to facilitate parent-infant interaction early, as it starts within the first days of infant’s life.\textsuperscript{45}

While most of these FCC models have focused on educating or supporting parents to enhance their coping skills and parenting capacity, Close Collaboration with Parents (CCP) program developed in Finland aimed to train NICU staff to improve their skills in collaboration with parents and to promote FCC.\textsuperscript{46} For a long time, many NICUs have failed to recognize parents as partners and parents have reported that they are not sufficiently included in their infants’ care.\textsuperscript{46} To succeed in FCC, it is necessary to develop a new relationship with parents which includes mutual respect, cooperation, and support for parents in every aspect of daily care among all staff of the NICU. Implementation of FCC in NICUs requires new role definitions among healthcare professionals to involve parents more in their infant’s care. In addition, informational support from the doctors, as well as nurses, must be incorporated to make FCC successful. This educational intervention for neonatal staff succeeded to improve the quality of FCC and to change the care culture in NICUs all over Finland.\textsuperscript{47,48} In this regard, the CCP program has a powerful potential to offer a breakthrough model in Korea for training the health care team to facilitate their communication and collaboration skills to support parental participation.\textsuperscript{48}

\textit{Single family room}

The concept of individual rooms for NICU patients had already been proposed in the early
The rationale for building single family rooms (SFRs) was to provide a calmer and more private environment for parents and their infant. In the SFR, the infant is less exposed to noise and artificial light from the intensive care settings. A more home-like and peaceful atmosphere for the family supports 24-hour presence of parents, privacy for pumping and breastfeeding, and SSC.

SFRs have been shown to not only enhance enteral nutrition, breastfeeding and growth, but also neurobehavorial function. It also reduces infections, apnea, risk of bronchopulmonary dysplasia and hospital stay compared to infants cared for in an open-bay unit. However, the greatest benefit is the development of a close parent-infant relationship and parental psychological well-being which can mediate the improvement of long-term outcomes of preterm infants. Even though there had been concerns raised regarding infants’ safety and staff stress, studies have revealed that SFRs decrease adverse physiologic events such as apnea, bradycardia, and desaturation. The neonatal care in SFRs was also reported to associate with less stress and better work satisfaction among nurses. It might be related to that they could focus more on their own professional role and facilitation of parenting, while letting parents perform infant care routines. Even though the cost per incubator was greater in the SFR model than in the open-bay model, the total cost of care was significantly reduced in an adjusted analysis including admission variables, treatment variables, respiratory variables, and length of hospitalization.

Beyond providing separate private spaces, the SFR model means that infant and family should be major considerations in the design of the NICU architecture. The SFR is generally equipped with an appropriate headwall for power, gas, and suction; an area for incubator, and family accommodations such as a fold-out couch, bed, recliner, closet, a
refrigerator for storing breastmilk or formula, a sink, and storage cabinets.\textsuperscript{50) In addition, materials used for facilities should be selected to control the environment such as sound-deadening walls and ceiling tiles which reduce ambient noise, or indirect overhead lights which can be fully regulated in accordance with the infant’s needs.\textsuperscript{50) Along with SFRs, space for families to congregate and to interact with their own and other infants’ family members also should be incorporated.\textsuperscript{57) These may include a lounge, dining area, waiting area, facilities for bathing, laundry, computer, and internet access, etc.

CONCLUSION

The basis of FCC is the recognition that the newborn infants are human beings in their own rights to be close to their parents, even they are sick or prematurely born. In addition, as they have immature central nervous system which is rapidly growing, to provide best possible conditions through bonding and attachment between parents and the infant is vital for proper development and better outcome. The key component of FCC is the parents’ presence in the ward, and their participation in the infant’s daily care and decision-making.

Until recently, most of NICUs have been closed to the infant’s family or parents, and parents were merely passive visitors in Korea. In addition, there has been a unique culture in Korea to separate the baby from the mother for mothers’ rest and recovery right after their delivery. This culture may hinder to introduce neonatal FCC in Korea. Changing the culture of care in NICUs is not easy. However, it is evident that the new paradigm of empowering parents in infant care in the NICU is valuable. Considering the benefits, now, it’s time to put FCC as a standard practice in caring for all sick infants of NICUs in Korea. In addition, adequate facilities providing private spaces for families and a hospital policy founded on a
friendly approach to families should be included. All of these changes must be combined with staff training to enhance their skills to collaborate with parents in NICUs.

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children.org/each-charter/


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# TABLES

## Table 1. The policy statement for family-centered care by American Academy of Pediatrics, 2012

<table>
<thead>
<tr>
<th>Value</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attitude</strong></td>
<td>1. Pediatricians should ensure that true collaborative relationships with families.</td>
</tr>
<tr>
<td></td>
<td>2. Pediatricians should unequivocally convey respect for families’ unique insights into the care plan.</td>
</tr>
<tr>
<td><strong>Collaboration</strong></td>
<td>3. Conducting attending physician rounds in the patient’s rooms with nursing staff and the family present should be standard practice.</td>
</tr>
<tr>
<td></td>
<td>4. Parents should be offered the option to be present with their child during medical procedures and offered support before, during and after the procedure.</td>
</tr>
<tr>
<td></td>
<td>8. Pediatricians should share medical information with families in ways that are useful and affirming.</td>
</tr>
<tr>
<td><strong>Administrative</strong></td>
<td>5. Pediatricians should advocate for improved employer recognition of the importance of family presence during hospitalization.</td>
</tr>
<tr>
<td></td>
<td>13. The design of health care facilities should promote the philosophy of family-centered care, such as including single-room care, family sleeping areas, and availability of kitchen and laundry areas and other areas supportive of families.</td>
</tr>
<tr>
<td><strong>Education/Study</strong></td>
<td>14. Education and training in family-centered care should be provided to all trainees, students and residents as well as all staff members.</td>
</tr>
<tr>
<td></td>
<td>16. Pediatricians should advocate for and participate in research on outcomes and implementation of family-centered care in all venues of care.</td>
</tr>
<tr>
<td><strong>Cost</strong></td>
<td>17. Payment for time spent with the family should be appropriate and paid to pediatricians without undue administrative complexities.</td>
</tr>
</tbody>
</table>
Table 2. Eight principles for neonatal family-centered care\textsuperscript{37)}

<table>
<thead>
<tr>
<th>No</th>
<th>Standard</th>
<th>Nature of evidences</th>
<th>Examples for neonatal intensive care units of Korea</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Free 24-hours a day parental access with no limitations due to staff shift or medical round</td>
<td>Human rights, Policy statements</td>
<td>Step-by-step expansion of visitation time, eventually unlimited parental visitation</td>
</tr>
<tr>
<td>2</td>
<td>Psychological support for parents</td>
<td>Meta-analysis</td>
<td>Focused parental interviews with psychologists</td>
</tr>
<tr>
<td>3</td>
<td>Neonatal pain management by parental holding</td>
<td>Meta-analysis</td>
<td>Parental bracing the infant during heel stick puncture</td>
</tr>
<tr>
<td>4</td>
<td>Controlling the quality of NICU environment (lighting and sound levels)</td>
<td>Meta-analysis</td>
<td>Use indirect lighting with a light regulator and noise decibel monitors</td>
</tr>
<tr>
<td>5</td>
<td>Neonatal postural support by parents</td>
<td>Meta-analysis</td>
<td>Educate parents how to hold, flex and calm the infant to a tucked position</td>
</tr>
<tr>
<td>6</td>
<td>Skin-to-skin contact</td>
<td>Meta-analysis</td>
<td>Kangaroo care from mother or father</td>
</tr>
<tr>
<td>7</td>
<td>Lactation and breastfeeding support for mothers</td>
<td>Meta-analysis</td>
<td>Lactation consultation to support mothers’ breastfeeding</td>
</tr>
<tr>
<td>8</td>
<td>Neonatal sleep protection</td>
<td>Animal studies</td>
<td>Flexible feeding schedule depends on neonatal awakened states</td>
</tr>
</tbody>
</table>
Table 3. Summary of representative family-centered care practice model in the NICU context

<table>
<thead>
<tr>
<th>Practice Model</th>
<th>To whom</th>
<th>Purpose</th>
<th>Who delivered</th>
<th>When/How long</th>
<th>Material</th>
<th>Origin</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant Behavioral Assessment and Intervention Program (IBAIP)(^{39})</td>
<td>parents</td>
<td>to interact with their baby effectively and responsively, using natural observations.</td>
<td>trained interventionists</td>
<td>home visits after discharge, monthly x 6-8</td>
<td>IBA tools</td>
<td>WA, USA</td>
<td>1989</td>
</tr>
<tr>
<td>Mother Infant Transaction Program (MITP)(^{38})</td>
<td>parents</td>
<td>to enhance interaction between more confident parents and their responsive infants</td>
<td>intervention nurses</td>
<td>1-hour daily for 7 days (after PMA(^{34}) 34-week) + 4 home visits after discharge (during the first 3 months)</td>
<td>tutoring material</td>
<td>NY, USA</td>
<td>1990</td>
</tr>
<tr>
<td>Guided Participation (GP)(^{40})</td>
<td>parents, less skilled nurses</td>
<td>to develop competencies in parenting to enhance their observation ability and sensitivity to babies’ cues</td>
<td>nurse/expert practitioners</td>
<td>45-minutes, weekly x 6</td>
<td>problem-solving domains</td>
<td>WI, USA</td>
<td>1998</td>
</tr>
<tr>
<td>Parent Baby Interaction Program (PBIP)(^{41})</td>
<td>parents</td>
<td>to enhance interaction between more confident parents and their responsive infants</td>
<td>research nurses</td>
<td>1-hour, weekly up to 6 weeks after discharge</td>
<td>program manual</td>
<td>Bristol, UK</td>
<td>1998</td>
</tr>
<tr>
<td>Creating Opportunities for Parent Empowerment (COPE)(^{43})</td>
<td>parents</td>
<td>to understand their roles</td>
<td>COPE director or assistants</td>
<td>4 phases</td>
<td>education material (booklets)</td>
<td>NY, USA</td>
<td>2004</td>
</tr>
<tr>
<td>Family Nurture Intervention (FNI)(^{43})</td>
<td>parents</td>
<td>to provide calming nurturing activities and interactions to their baby to enhance parenting capacity</td>
<td>trained Nurture Specialists</td>
<td>1-hour, at least 4 sessions/week</td>
<td>manual, baby front carrier</td>
<td>NY, USA</td>
<td>2012</td>
</tr>
<tr>
<td>Positive Parenting Program (Triple P)(^{42})</td>
<td>parents</td>
<td>to enhance parenting capacity</td>
<td>trained Triple P provider</td>
<td>2-hours, x 4 sessions</td>
<td>17 parenting strategies</td>
<td>Brisbane, Australia</td>
<td>2013</td>
</tr>
<tr>
<td>Family Integrated Care (FiCare)(^{44})</td>
<td>parents, NICU Staff, hospital managers</td>
<td>to integrate families as partners in the NICU care team</td>
<td>self-learning from tools and information provided at websites</td>
<td>various depending the subjects (e.g., a 4-hour course for NICU staff)</td>
<td>FiCare Toolkit &amp; e-resources</td>
<td>Toronto, Canada</td>
<td>2013</td>
</tr>
<tr>
<td>Close Collaboration with Parents(^{59})</td>
<td>NICU Staff</td>
<td>to develop staff skills in collaborating with parents and promote FCC(^{5})</td>
<td>trained mentors</td>
<td>4 phases for 18 months</td>
<td>bedside practice tools, e-learning</td>
<td>Turku, Finland</td>
<td>2014</td>
</tr>
<tr>
<td>Early Collaborative Intervention (EACI)(^{45})</td>
<td>parents</td>
<td>to develop an early parent-infant interaction</td>
<td>NIDCAP(^{40})-certified nurses</td>
<td>3 sessions: within 72h after birth, within 48h before discharge, and when full-term</td>
<td>hands-on guidance</td>
<td>Linköping, Sweden</td>
<td>2021</td>
</tr>
</tbody>
</table>
First published in the peer reviewed journal; b) Postmenstrual age; c) Family-centered care; d) Newborn Individualized Developmental Care and Assessment Program.