Family-Centered Care for Newborns: From Pilot Implementation to National Scale-up in India

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Family-centered care (FCC) is a well-evidenced approach, recognized as the standard of care for newborns and children. This approach promotes a mutually beneficial partnership between health professionals and infant/young children's families, providing an opportunity for developing trustful relations and transparency of care. Implementation experience from our newborn intensive care unit highlighted three prerequisites for successful implementation, which include adequate infrastructure and basic amenities for the primary caregiver; attitudinal change amongst healthcare providers accepting parents/family as partners in the care of the newborn; and active involvement of primary caregivers in baby care activities alongside the nurses. Healthcare providers played a crucial role in empowering parents, improving their confidence and competence to transition into the role of primary caregivers after discharge. FCC contributes to all domains of nurturing care and has relevance in newborn care and pediatric care at all levels, with scope for being expanded to the antenatal and postnatal period to promote early childhood development. With national scale-up in progress, addressing actual or perceived barriers to implementation requires context-specific adaptation and the best use of opportunities and funding support available under the national health program.

Keywords: *Early childhood development, Family integrated care, Family participatory care, Nurturing care*.

Family-centered care (FCC) is an approach to care delivery that promotes a mutually beneficial partnership among mothers, families, and health- care providers to support healthcare planning, delivery, and evaluation. The core principles of FCC are information sharing, participation, collaboration, mutual respect between health professionals and the infant/young child's family. The basic idea is to involve parents in caring for their sick newborns and responding to their parents' needs and rights. Parents are empowered and encouraged to participate in responsive caregiving to their sick/small neonate while offering him/ her tender love, affection, and soothing touch. FCC initiates a vital interaction with the baby in the early development period and lays the foundation for lifelong bonding with the parents. FCC is a humane way of care to get the baby back within the family's embrace where s/he belongs.

FCC impacts early childhood development by addressing the developmental needs of the small and sick newborn. It protects them from the damaging effects of separation during inpatient care as the parents can provide critical developmental support to the newborn, such as safe-guarding sleep, promoting appropriate sensory interaction (i.e., smell, touch, sound), monitoring and managing pain and stress, and creating a healing environment. Developmental aspects of FCC are especially important in preterm babies. Several studies support the existence of a sensitive bonding and attachment period in preterm neonates, similar to that in full-term newborns. The parent's ability to adjust to preterm birth and the quality of early parent-infant relationships are suggested to be critical aspects that impact the development and acquisition of competencies later [1] (**Web Fig. 1**).

AN IMPLEMENTATION MODEL

Although FCC is a well-evidenced approach, its translation into an implementable model is still evolving. We describe in this paper the pilot initiative at the neonatal intensive care unit (NICU) of Dr. Ram Manohar Lohia (RML) Hospital, New Delhi, to translate and adapt FCC principles into a feasible, acceptable, and sustainable model of FCC and its eventual scale up in the public health system [2].

The FCC model of care delivery varies across the newborn care units, globally. Some level III units provided psychosocial support and counseling for parents [3], while in others, parents were given information about preterm infants' appearance and behavioral characteristics and provided with audiotaped material on parenting care (COPE trial) [4]. In yet another FCC model, parents visited the baby for a limited time and attended medical rounds [5]. Another model allowed parents to stay with their newborn in a NICU level II, step-down room from admission until discharge [6]. A more recent study provides the scientific evidence for the eight principles for patient-centered and FCC for newborns, which include free parental access, sleep protection, pain

management, postural support, skin-to-skin contact, support for breastfeeding and lactation, a supportive environment that reduces sensory stimuli and psychological support for parents [7].

Our implementation model focused on moving away from a predominantly 'provider-centric' model of care to a 'shared' model, where parents and healthcare providers worked together to ensure the well-being and survival of newborns. After admitting a sick newborn, the first step was to identify the primary caregiver, a person willing to devote time to participate in the care of the sick newborn, from amongst the accompanying family attendants. In our unit, this primary caregiver was usually the mother, but if not available, the father or grandmother was recruited until she recovered. A trained team of healthcare providers, usually the nurses, engaged with the primary caregivers through daily sessions held in the newborn care unit at a pre-specified time. The sessions were designed to provide information and skills for baby care activities through demonstration and practice. Once the primary caregiver learned the basic skills such as hand hygiene and the entry protocol (e.g., gowning), they engaged in baby care activities inside the newborn care unit, supervised by the attending nurse. Peer-to-peer learning was encouraged; new mothers learned from those mothers who had a longer stay, thus helping boost confidence as they related well to each other's experiences. Gradually, each new mother/primary caregiver acquired skills for performing essential care activities of their small and sick newborns, preparing them for independently caring for their babies at home after discharge. Besides direct involvement in caring for the baby, the parents' needs for information about their baby's condition, guidance, and support were met through respectful communication by the unit's doctors and nurses (**Web Fig. 2**).

Results and Key Learning

Evidence suggests that FCC has benefits, both in terms of improvement in practices related to care and health outcomes. A randomized controlled trial (2010-12) conducted in our NICU, demonstrated that there is improvement in exclusive breastfeeding rates with FCC (pre-discharge exclusive breastfeeding rates 80.4% vs 66.7%; *P*=0.007), with no difference in the incidence of nosocomial episodes of sepsis between groups [8]. The FCC approach helped us establish a continuum of care for high-risk newborns across the health facility and home, and improved the adherence to discharge instructions and follow-up visits amongst babies discharged from our unit. While the primary caregivers experienced satisfaction and empowerment by engaging with their newborns, it also provided transparency of care and fostered the development of trust between healthcare providers and caregivers.

While our FCC model appears simple, we found that there are three prerequisites for successful implementation. Firstly, basic amenities for mothers/attendants such as washroom facilities and sleeping quarters close to the newborn care unit should be in place. In addition, a designated space for conducting training and counseling sessions is desirable. Secondly, attitudinal change amongst the healthcare providers to accept parents/family as partners and embrace core components of family participation and equal partnership in care is a prerequisite. While the parents'/family's 'buy in' comes readily, we found that healthcare providers' 'buy in' was the most significant challenge. To let go of one's position of authority and control and transition to a new dynamic of respectful partnership with the parents who are conventional 'receivers' of care requires significant behavioral modification. There were feelings of diminished authority and being held accountable to deliver a higher standard of care as the parents were now better informed and constantly present. Thirdly, for a unit to qualify as implementing FCC, there must be a visible change where mothers/primary caregivers are seen actively participating in baby care activities under the supervision of the nurses. However, with this comes the risk of over-reliance and task shifting by the conventional care provider (doctor/nurse) to the primary caregivers, even though the primary responsibility for medical care rests with the health providers. This situation can be circumvented by putting in place a framework that clearly describes the baby care activities that primary caregivers can take on, and which ones continue to be the domain of the care providers.

Piloting and Scaling-Up

After the initial study results from our unit [8], we partnered with Norway India Partnership Initiative (NIPI) to adapt our FCC model for the secondary level newborn care facilities in the public health system. In 2014, this was piloted in five special newborn care units (SNCUs) across five different states. Encouraged by positive changes at these five demonstration sites, FCC was scaled up by the respective state governments to 69 more districts by the end of 2017, using National Health Mission (NHM) funds. In a rapid assessment conducted in 38 of these district SNCUs, the health providers' perception was that the quality of care, breastfeeding and KMC practices had improved, with better adherence to follow-up and continued exclusive breastfeeding and kangaroo mother care rates at home [9].

With the emerging evidence and recognizing the potential for scale-up across the extensive network of SNCUs, the Ministry of Health and Family Welfare (MoHFW) brought out the National operational guidelines for family participatory care in 2017 [10], paving the way for FCC across all newborn care units, and making federal

funding support available for this purpose. Under the national program a culturally sensitive comprehensive audio-visual training package for family participatory care was made available to standardize the content delivery of the sessions conducted for the primary caregivers. This package includes the audio-video training tool and a training guide package covering practices related to infection prevention, including hand washing and entry protocol; providing developmentally supportive care; activities of routine care, including feeding (technique of breastfeeding, expression of breast milk, and assisted feeding of a low birth weight baby) and diaper change; kangaroo mother care; and preparing parents and family for discharge and post-discharge care of the high-risk baby at home (continuing essential newborn care practices, recognizing danger signs, and timely care-seeking in the event of sickness).

THE WAY FORWARD

FCC features prominently in various recent global framework documents and action plans. The World Health Assembly adopted the Integrated people-centered health services (IPCHS) framework in 2016, acknowledging that family members play a critical role in healthcare delivery across all patient age groups and affirming the need to empower and engage them as partners. This framework is particularly relevant for newborn babies who require intensive caregiving to fulfill their basic needs and protect their rights [11]. The nurturing care framework for early childhood development, 2018 includes FCC as one of the five guiding principles, acknowledging that parents and close family members are at the center of nurturing care provision [12]. The recent WHO, and UNICEF report 'Survive and Thrive: Transforming care for every small and sick newborn; 2019, highlights the need to invest in quality neonatal care that is developmentally supportive and nurturing [13]. FCC is included as one of the eight WHO 'Standards for the care of small and sick newborns in health facilities' launched in 2020 [14]. These global documents position family-centered care as a central tenet for programming for mothers, newborns, and children.

A shift towards a healthcare model that embraces family participation in newborn care requires reasonable investments in health systems and flexible implementation. Given the regional, demographic, and socio-cultural diversities across the states of India, contextual adaptations in the model is required. Implementors may be concerned about actual or perceived barriers such as a lack of sufficient space inside newborn care units, inadequate infrastructure for accommodating the caregivers, staff shortages, the perceived risk of infection through caregivers, security considerations, interference with workflow, concerns about task-shifting, and inability to participate or lack of interest on the part of family members. Thus, the implementation requires a baseline need-gap assessment and tailoring implementation state-wise with strong leadership by local champions and backed by political commitment.

Within the India Newborn Action Plan 2014, FCC contributes to its two pillars: newborn care and care beyond newborn survival [15]. The large-scale roll-out of FCC in India will benefit from concerted efforts for health system strengthening, cascaded capacity building, and ongoing support for newborn care with a quality assurance component built into the program. Various provisions are available for infrastructure strengthening under the National Health Mission to make health facilities family-friendly but requires commitment from the health facility team (including administrators) and district and state program managers. With the new maternal and child health Wings coming up at the district level, some infrastructural challenges are likely to be mitigated.

For making the services and the facility family-friendly, a change in mindset and attitude of each cadre of the healthcare team is essential. The experience from our unit and the pilot sites is that when care providers reach the stage of understanding and accept the value of equal and respectful partnership with caregivers, they not only experience a sense of fulfillment and job satisfaction by supporting FCC but also become champions for furthering this approach amongst their peers.

Currently, FCC approach is being implemented only in the newborn care units. However, the scope of FCC can expand to cover intrapartum and postpartum care and pediatric care. FCC approach lends itself well to adoption in facility-based newborn care at all levels (SNCU, Newborn Stabilization Units, KMC units), home-based care of newborns and young children (HBNC, HBYC programs), LAQSHYA (labor room quality improvement initiative), and pediatric care units. The existing training package for FCC can be well-adopted to orient mothers/parents on responsive caregiving and essential newborn care practices in post-natal wards across public health facilities and reach out to more caregivers during the newborn period.

CONCLUSION

FCC creates an environment that is culturally sensitive and responsive to the family's psychosocial needs, facilitates lactation, empowers families, helps them cope with inadequacies and stresses of unprepared parenting, builds trustful relationships with healthcare providers, and overall provides a positive healthcare experience. Parents can make unique contributions to the care of their small and sick newborn, and the healthcare team can bolster parents' confidence and competence to help them transition into the

role of primary caregivers. This empowerment can foster greater maternal and paternal emotional coping while improving parenting abilities for these fragile newborns [16].

From the public health perspective, FCC can act as a bridge between facility-based and home-based newborn care. Operational feasibility and acceptability in Indian public healthcare settings seem to be promising and benefit the poorest and most vulnerable newborns managed in public sector facilities. It can also improve gender equality by sensitizing and involving both mothers and fathers equally in caring for their newborns. FCC for small and sick newborns and is the key to optimizing early childhood development through nurturing care during the critical periods of their early neurodevelopment.

Note: DA is a staff member of the World Health Organization. The author alone is responsible for the views expressed in this paper and they do not necessarily represent the decisions, policy or views of the World Health Organization.

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Web Fig. 1 The process of institutionalizing family-centered care.

Web Fig. 2 The linkage between family-centered care and early childhood development.