



Implementing Family-Centered Care in the Neonatal Intensive Care Unit – A Quality Improvement Initiative

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Abstract

Objective The present study aims to implement family-centered care (FCC) in neonatal intensive care unit (NICU). FCC facilitates mother-infant bonding with benefits for both families and health system. The authors used quality-improvement (QI) methods to implement FCC in level-2 NICU from an existing baseline of 30% to 80% over a period of 6 mo.

Methods Using the Institute of Healthcare model for improvement, the authors implemented strategies for family participation in caregiving activities, oral feeding and kangaroo care for neonates admitted in level-2 NICU. Eligibility criteria included the availability of at least one family member, preferably the mother for at least 6 h/d and a stable neonate based on physiological criteria irrespective of gestational age. The key interventions were: (1) adoption of a unit protocol for FCC with expanded visitation hours; (2) parental education through audio-visual aids, and (3) capacity building through training and peer support.

Result Between August 2019 and January 2020, 1587 neonates were admitted to the NICU and 505 admitted in level-2 were enrolled. The proportion of eligible mother-infant dyads participating in FCC increased from a baseline of 32% to 44% during intervention and to 66% in the postintervention phase. The number of days per month FCC was tracked increased from 67% in the baseline to 82% in postintervention phase. There was no increase in the incidence of sepsis after implementation of FCC.

Conclusion Orientation of parents to FCC using audio-visual aids, provision of hands-on training and peer-support facilitated them to become active participants in their neonates' care.

Keywords Family-centered care · Quality improvement · Capacity building · Neonatal sepsis

Introduction

The advances in neonatal care has improved the survival and outcomes of preterm and sick neonates admitted to neonatal intensive care units (NICU) [1]. Parents of sick neonates admitted to the NICU experience stress, anxiety, helplessness, and depression and perceive the NICU environment as alien and intimidating [2]. Family-centered care (FCC) is a mutually beneficial and collaborative partnership between patient, family and healthcare system [3]. Involving parents in active caregiving activities enables them to feel more supported, connected to their babies and improves their confidence. FCC has been shown to

improve clinical outcomes in neonates like better growth parameters at discharge and shorter NICU stay [4]. Kangaroo mother care (KMC), an important component of FCC improves breastfeeding rates, reduces mortality, sepsis and hospital-stay [5]. Neonates cared for in single family room NICU show better neurobehavior in terms of less physiologic stress, hypertonicity, and pain [6]. Parents have a positive perception about FCC and feel that it improves their competence in neonatal care and discharge preparedness [7]. The health system also benefits from FCC in terms of shorter NICU and hospital stay of infants, wiser allocation of the resources, and better parent-infant bonding [8].

Despite the various benefits of FCC, its implementation in low- and middle-income countries is low. Barriers include staff shortages, large number of admissions with overcrowding, parental fear, social and cultural barriers, lack of privacy, inadequate infrastructure or space to accommodate families in hospital, inadequate educational support provided to families, and lack of policy and leadership support [9]. A randomized controlled trial from a public tertiary care hospital in India

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showed the feasibility of implementing FCC in NICU without an increase in sepsis in the unit [10]. Therefore, in August 2019, the authors initiated a quality improvement (QI) project to implement family participation in the care of sick neonates in the level-2 NICU. The authors' specific aim was to increase the percentage of mothers participating in FCC activities from a baseline of 30% to 80% by January 2020 through parental education and capacity building.

Material and Methods

Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER), Puducherry is a tertiary care teaching centre in South India. The JIPMER NICU has bed strength of 60 and it caters to an average of 16,000 deliveries and 2800 admissions to the NICU per annum. It has 3 levels of care. The level-3 area has 14 beds and is designated for initial care of preterm and sick neonates of all gestation requiring mechanical ventilation, inotropic support or therapeutic hypothermia. Fifteen bedded level-2 is a step-down area for level-3 NICU and also manages sick neonates who are not critically ill. Therapies offered in level-2 include noninvasive respiratory support, intravenous fluids, antibiotics, phototherapy, and parenteral nutrition as required. Level-1 with 31 beds is a care-by-parent area where mothers are directly involved in all caregiving activities under the supervision of nurses. At any one point, 80 neonates (bed occupancy rate of 110%–120%) are admitted across all 3 levels. The NICU supervising team consists of three neonatologists, six residents, and two interns. Nurses work in three shifts in the NICU and the nurse patient ratio is 1:4 in level-3, 1:6–8 in level-2 and 2 nurses in level-1.

Mothers visit the NICU to breastfeed, express milk and to provide kangaroo mother care (KMC). Parents are counseled each day about their neonates' condition in a dedicated counseling room. Following this, the families visit their babies in turns. The nurses use this opportunity to talk to mothers and to help initiate KMC by the bedside. While the concept of FCC existed in the unit before this QI project, the authors did not have a formal policy or operating procedures for parental education and capacity building. Logistic barriers included restrictive visitation hours, staff shortage, higher workload, lack of family awareness and teaching resources in local language (Tamil).

Three nursing officers and two senior residents led this QI project supervised by two neonatologists. The study was approved by the Institutional Ethics Committee which granted waiver of parental consent for enrollment. The authors followed the 'model for improvement' and introduced iterative changes using plan-do-study-act (PDSA) cycles.

To be eligible for enrollment, the authors required the availability of at least one family member preferably the

mother (or the grandmother) who could dedicate at least 6 h/d between 9 am to 5 pm for neonatal care, and a stable neonate. The neonate was considered stable if less than two parameters of TOPS (Temperature, Oxygen saturation, Perfusion, Sugar) score were abnormal [11]. TOPS score includes assessment of temperature (abnormal if <36.5 °C) oxygen saturation (abnormal if $<90\%$), capillary refill time (abnormal if ≥ 3 s) and blood sugar (abnormal if <40 mg/dl). Eligibility was decided on a daily basis by resident doctors and communicated to nursing staff. The neonates were excluded from FCC if they required noninvasive respiratory support (other than blended oxygen by cannula), had major congenital malformations or were admitted for comfort care.

In the baseline phase (August 2019), the authors did not introduce any changes to the system. They measured the proportion of eligible mother-infant dyads participating in FCC activities. They performed a cause-effect analysis using a fishbone diagram (Fig. 1) and constructed a driver diagram to identify key change ideas (Fig. 2). A traditional unit design with strict visitation policy, negative staff attitudes due to fear of sepsis, lack of resources, uncertainty about how to support and train parents, overcrowding, lack of time and apprehension among mothers to handle sick neonates were identified as important barriers.

In the intervention phase (September–November 2019), the authors followed the operational guidelines laid down by the Ministry of Health and Family Welfare (MoHFW), 2017 for the implementation of FCC in public health facilities [11]. The interventions were designed to standardize teaching and hands-on training provided to parents. Activities were targeted for weekdays because of staffing limitations on weekends. The authors used the following tools for parental education and capacity building.

To suit the local context, the authors made videos in Tamil language with inputs from nurses and residents. The objective of this tool was to introduce the parents to the NICU environment and the various ways they could contribute to neonatal care. These were streamed continuously in the television of NICU waiting area and available for all parents irrespective of whether enrolled in the study or not. The videos covered three aspects: entry into NICU (information about do's and don'ts before entry, learning steps of hand washing and wearing a gown); second, related to familiarization with the NICU environment; and third, discharge preparedness and care at home. At NICU entry, parents were supervised and assisted by a nurse to adhere to hand-washing and gowning.

Hands-on training was provided to mothers tailored to their learning capacity and neonatal needs. Training comprised demonstration of caregiving activities (diaper-change, orogastric tube feeding and paladai feeding) by the bedside nurse followed by supervised practice. Once the nurse was confident that the mother had mastered the technique, she was allowed to do it independently. Kangaroo mother care, breastfeeding,

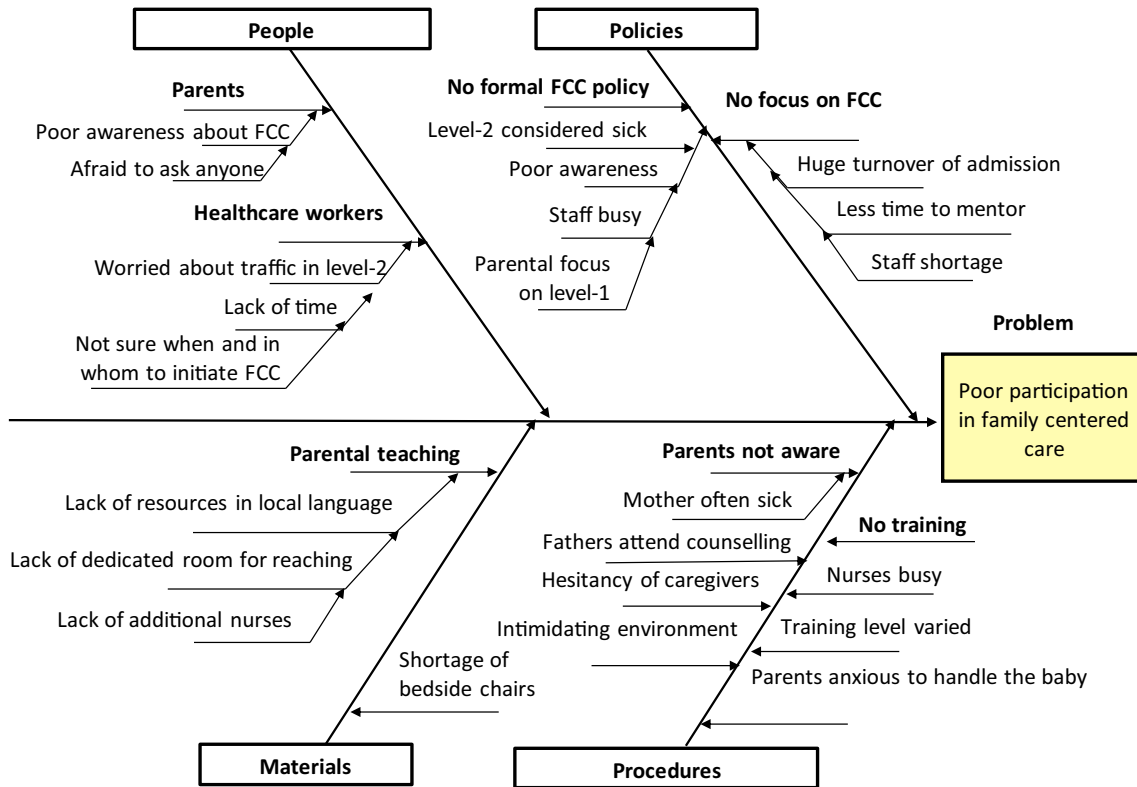


Fig. 1 Fishbone analysis to understand the barriers in implementing family-centered care (FCC). KMC Kangaroo mother care

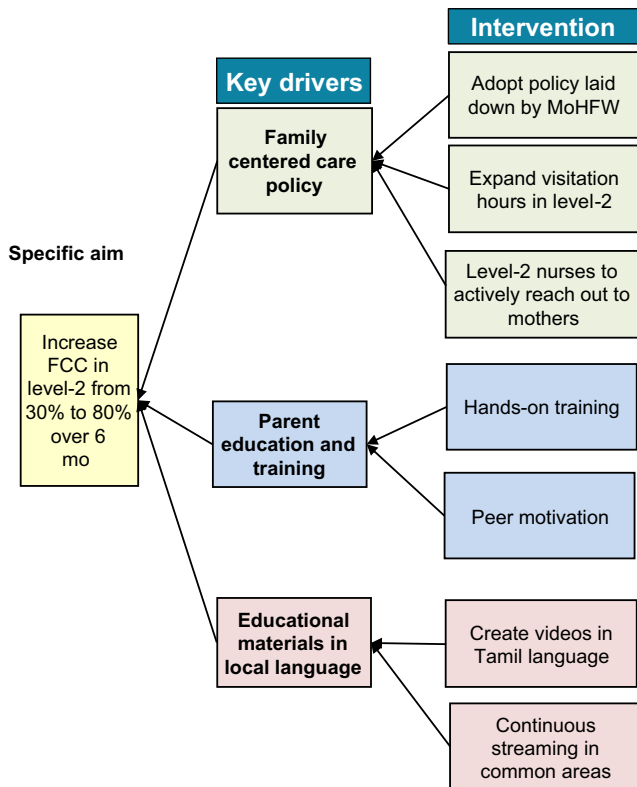


Fig. 2 Key driver diagram. FCC Family-centered care; NICU Neonatal intensive care unit

and milk expression were also supported. Procedures like fixation of intravenous or nasal cannula, weighing or vital sign monitoring were done only by the nurses.

As the literacy level and learning time may differ from one parent to another, they may attain competencies at their own pace. Hence, the authors considered their participation in any of the caregiving activities to be counted for FCC. They did not formally assess their knowledge or competencies.

PDSA cycles: Two PDSA cycles were done over 3 mo (Table 1) to implement FCC in the unit. The outcomes were tracked and discussed during monthly face-to-face meeting with stakeholders.

In the postintervention phase (2 mo), the authors evaluated the continued implementation of FCC and used a stamp in the neonatal case file to notify resident doctors and nurses as soon as the baby was enrolled for FCC.

Primary outcome measure was the proportion of eligible mother-infant dyads participating in FCC. The authors used a register to track this outcome which was calculated as the number of neonates receiving caregiving activities by a family member divided by the total number of eligible neonates listed on that day. The process measure was the daily documentation of eligibility exercise per month in the FCC register. The balancing measures included were the number of episodes of culture positive sepsis per 100 NICU admissions during the

Table 1 Plan-do-study-act worksheet for implementing family-centered care

Aim: Improve family participation in level-2 NICU from a baseline of 30% to 80% over a 6 mo period

Outcome measure: Proportion of eligible mother-infant dyads participating in FCC activities daily

Process measure: Identification of eligible dyads daily and documentation of caregiving procedures in FCC register

Balancing measure: Incidence of culture positive sepsis per 100 admissions in the unit during study period

PDSA cycle#1 (September–October 2019)

Plan: Form a unit policy on FCC for implementation in level-2

Do: Unit policy on FCC based on existing guidelines encompassing

- Expanded visitation time in level-2
- Staff orientated to new policy
- Educational videos in Tamil language to orient parents
- Bedside nurse to train mothers in neonatal care, feeding and kangaroo care

Study: FCC improved from 32% to 44%

Initial reaction from staff was welcoming. Greater need for bedside chairs for parents identified. Staff members noted that mothers do not consistently turn-up daily and need to be called daily

Act: Increase staff motivation using regular updates and monthly meeting

Arrange more bedside chairs

PDSA cycle#2 (November 2019)

Plan: Identify FCC champion mothers to motivate new entrants (peer motivation)

Do: FCC champions identified. We arranged two informal focused group discussion to obtain feedback from mothers and identify problems

Study: FCC improved to 66%

Act: The FCC policy and peer motivation were acceptable to all stakeholders. A stamp indicating FCC participation was made in neonatal case file as a reminder

FCC Family-centered care

study period and any inadvertent adverse event directly attributable to family participation.

Statistical process control (SPC) charts were used to track the primary outcome and balancing measures. The primary outcome was represented as a p chart. The control limits on the charts (upper and lower) correspond to three standard deviations above or below the mean. Common cause variations lie within the control lines. Points outside the control limits indicate a special cause variation requiring investigation and action.

Results

Between August 2019 and January 2020, a total of 1587 neonates were admitted to the NICU. The average daily census in Level-2 NICU was 24 during the study period. The number of mother-infant dyads enrolled in baseline, intervention and postintervention phases were 98, 258, and 149, respectively

(twins and triplets counted as single dyads). The proportion of eligible mother-infant dyads participating in FCC each day is depicted in the p chart in Fig. 3. During the baseline phase, this proportion was 32% and improved to 44% following the introduction of standardized FCC policy and peer mentoring. This further improved to 66% in the post intervention phase. The number of days per month FCC was tracked increased from 67% baseline to 76% during intervention and 82% in post intervention period. In the baseline, participation in FCC involved mainly kangaroo care with few mothers involved in feeding and caregiving. This improved during the study period with mothers equally doing all the three activities (Fig. 4).

The SPC chart for the incidence of culture positive sepsis in the NICU before the QI was 13.6 per 100 NICU admissions and did not show any increase (6.6 per 100 NICU admissions) after the implementation of QI in the unit (Fig. 5). No adverse life-threatening events directly attributable to parental caregiving activity were observed during the study period.

Discussion

The present study represents the use of QI methods to implement FCC in a level-2 NICU with high-patient load and limited staff. The proportion of eligible mother-infant dyads participating in FCC increased from 32% at baseline to 66% after implementation although we fell short of our target of 80%. There was no increase in the incidence of culture positive sepsis during the study period. Standardized protocols, bundles, and checklists are an important strategy to implement evidence-based practices in the NICU. In the present case, the educational package was customized to our system and implemented using two PDSA cycles.

Parental education and hands-on training were led entirely by nurses with physicians providing a supportive role. No additional staff other than NICU nurses were involved in the implementation. Another unique feature of this NICU is that level-1 is entirely a care by parent area and the authors focussed on implementing FCC in level-2 area. Therefore, the study results should be interpreted in this context.

There were challenges in implementation. The authors did not have dedicated equipment or a separate room with adequate seating capacity for training parents. Hence, videos were streamed in the waiting area and focus was given on hands-on training. Additional bed-side chairs for KMC were provided by a generous donor. The staff were initially concerned about overcrowding and increase in sepsis rates. The nursing officer in charge of this project identified change leaders among nurses and mothers and empowered them to work towards a common goal. The monthly review of run charts and informal discussions with parents provided feedback and positive

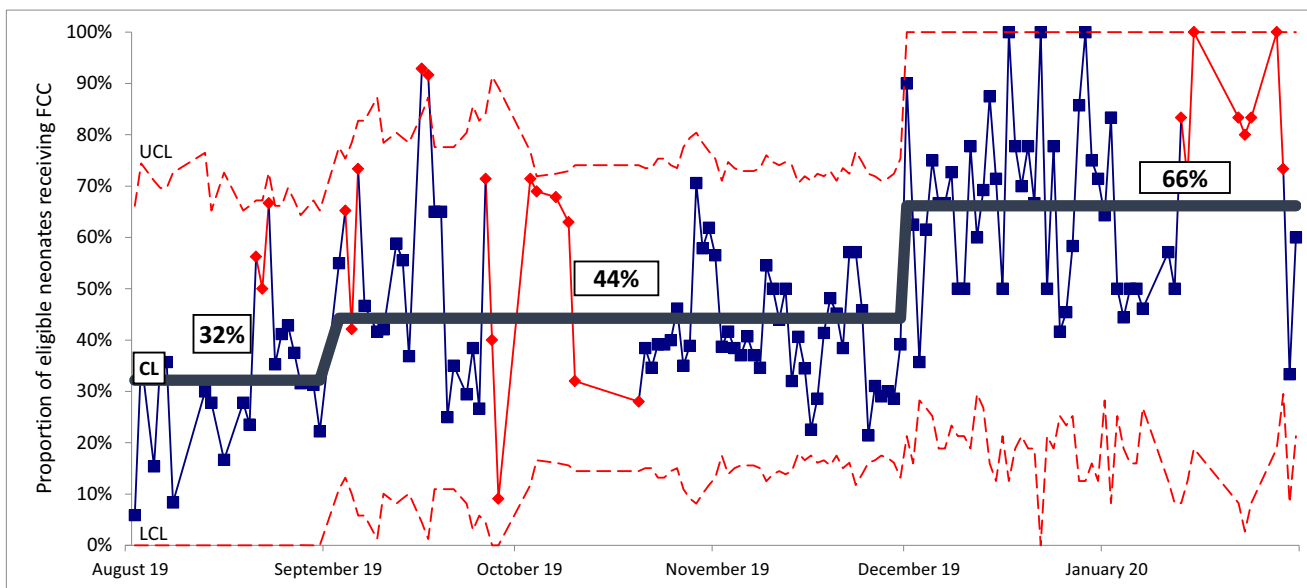


Fig. 3 Statistical process control P chart depicting proportion of eligible mother infant dyads participating in FCC. Y axis represents the proportion and X axis depicts time. The central line is the mean and

upper control line (UCL) and lower control line (LCL) correspond to +3 and -3 standard deviations. FCC Family-centered care; PDSA Plan-do-study-act

reinforcement. To avoid staff overburden, the authors tracked only essential outcomes and did not insist on documenting training sessions conducted.

Successful implementation of FCC in the NICU depends on many factors, like introduction of behavioral change in staff, addressing family needs, communication, and leadership support. Nurses need in-service education about FCC, and staff shortage needs to be addressed to prevent fatigue and stress. They need support as the transition from the traditional

care model to FCC approach is complex and gradual. Exploring the experience of nurses in the present study would have provided more information. To sustain family participation in NICU, constant education and parental support are needed and should cater to the varying caregiver profiles, skill sets, and competency. Peer support provided by volunteer parents in the NICU is a unique form of assistance that is recognized to increase confidence, well-being, coping skills and self-esteem among other parents [12]. However, it is

Fig. 4 Average number of mothers providing various aspects of family-centered care per day. KMC Kangaroo mother care

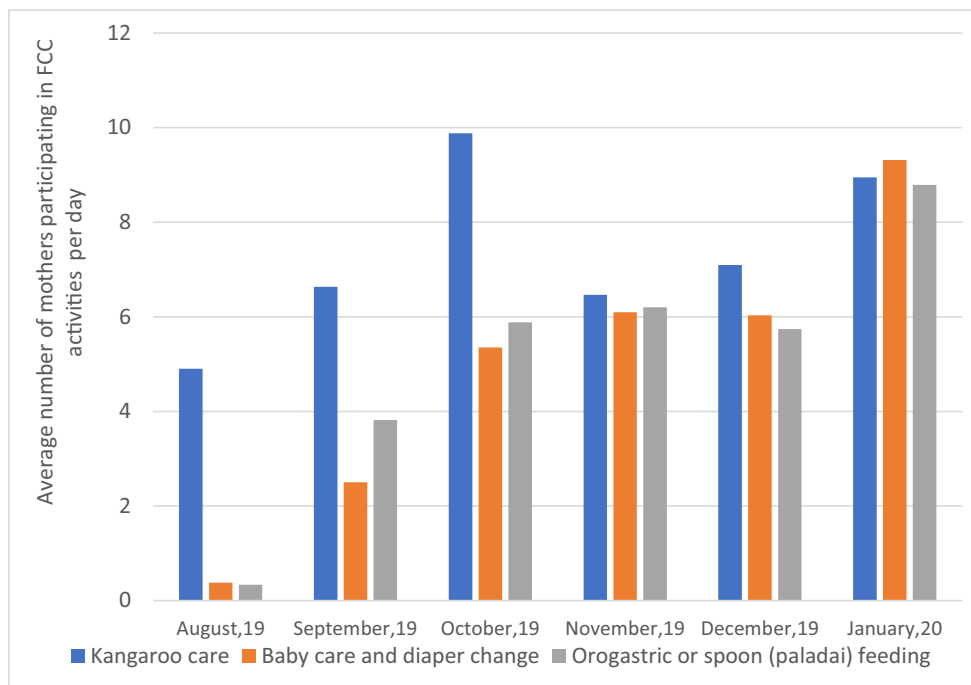
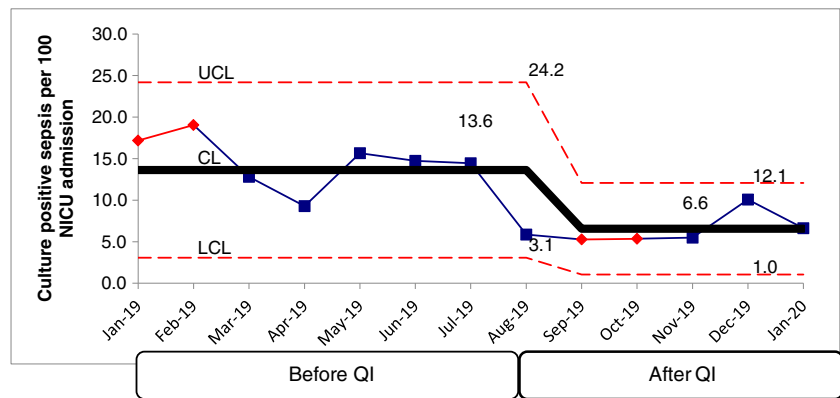


Fig. 5 Statistical process control chart depicting number of culture positive sepsis per 100 NICU admissions each month from Jan 2019 to Jan 2020. The central line is the mean and upper control line (UCL) and lower control line (LCL) correspond to +3 and -3 standard deviations. *PDSA* Plan-do-study-act



intended not to replace or duplicate the professional support provided by healthcare workers. While the authors received positive feedback with peer support in the present study, the degree of support was not formally evaluated. The criteria for selection of volunteer peer mentors, and the roles they play are variable and need to be laid down before a formal support program is established. Structural limitations like visitation policy, organizational barriers, socio-cultural barriers like limiting father's role also need to be addressed [13]. Hospitals in resource limited settings often do not have facilities to accommodate the mothers or provide only a common sleeping room.

In India, FCC was implemented at five district special care neonatal units (SNCU) and later expanded to 104 units, with a proposal to scale up further [14]. An assessment of 38 facilities proved the feasibility of implementation as well as improved rates of exclusive breastfeeding, KMC and lesser postdischarge mortality [15]. Another recent concept introduced in a tertiary care hospital in India is Mother-NICU (M-NICU) where mother stays with the neonate throughout the NICU stay with her bed laid near the baby's warmer. Initial results showed that mothers can be easily trained to monitor neonates and maintain asepsis routines in the M-NICU. Similar models in high income countries have shown improved neonatal outcomes like reduced duration of hospital stay, early initiation of breastfeeding, and lesser parental anxiety and better neurobehavioral outcomes [6].

The present QI project has few limitations. Given the known benefits of FCC, the authors focused their efforts on a process measure (proportion of mother-infant dyads engaged in FCC) as opposed to a patient-centered outcome, such as exclusivity of mother's milk feeding, duration of hospital stay or parental competencies. The authors could train only the primary caregiver (assumed to be the mother) and the grandmother was approached only if the mother was unwell or not available. Fathers were allowed visitation rights but not trained for caregiving activities, as their presence was felt to infringe on the privacy of other mothers to breastfeed or perform KMC in the unit. Similar attitude towards fathers in the NICU has been reported in other studies and may stem from unit culture, traditional and religious views of the family and the staff [9, 16]. Future studies should

consider family participation as a unit and explore the experience of fathers in NICU. Evaluation of long-term sustainability of FCC is important and needs to be studied in relation to environmental, social and economic resources.

The general framework of FCC used in our setup is transferable to other neonatal units in similar settings. Parents can be involved in many caregiving activities including developmentally supportive care, management of pain and stress, taking part in family rounds, and as members of various advocacy groups.

Conclusions

This project revealed the feasibility of using QI methodology to implement FCC for sick neonates in a level-2 NICU. Orientation of parents to FCC using audio-visual aids, provision of hands-on training and peer support facilitated them to become active participants in their neonates' care.

Authors' Contributions SS: Concept, design, data collection, analysis and draft of manuscript; BA: Design, supervision of implementation and critical review of manuscript; RS, NP, RM: Implementation, training and data collection; CK, KC: Data collection, implementation, analysis and draft of manuscript; SS: Acts as the guarantor of the paper.

Compliance with Ethical Standards

Ethics Approval Ethics approval obtained. Institute Ethics Committee granted waiver of consent from parents.

Conflict of Interest None.

References

1. Te Pas AB. Improving neonatal care with technology. *Front Pediatr.* 2017;5:110.
2. Obeidat HM, Bond EA, Callister LC. The parental experience of having an infant in the newborn intensive care unit. *J Perinat Educ.* 2009;18:23–9.

3. Committee On Hospital C, Institute For P, Family-Centered C. Patient- and family-centered care and the pediatrician's role. *Pediatrics*. 2012;129:394–404.
4. Johnston AM, Bullock CE, Graham JE, et al. Implementation and case-study results of potentially better practices for family-centered care: the family-centered care map. *Pediatrics*. 2006;118:S108–14.
5. Conde-Agudelo A, Diaz-Rossello JL. Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. *Cochrane Database Syst Rev*. 2016;8:CD002771.
6. Lester BM, Hawes K, Abar B, et al. Single-family room care and neurobehavioral and medical outcomes in preterm infants. *Pediatrics*. 2014;134:754–60.
7. Sarin E, Maria A. Acceptability of a family-centered newborn care model among providers and receivers of care in a public health setting: a qualitative study from India. *BMC Health Serv Res*. 2019;19:184.
8. Melnyk BM, Feinstein NF, Alpert-Gillis L, et al. Reducing premature infants' length of stay and improving parents' mental health outcomes with the creating opportunities for parent empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. *Pediatrics*. 2006;118:e1414–27.
9. Mirlashari J, Brown H, Fomani FK, de Salaberry J, Zadeh TK, Khoshkhou F. The challenges of implementing family-centered care in NICU from the perspectives of physicians and nurses. *J Pediatr Nurs*. 2020;50:e91–8.
10. Verma A, Maria A, Pandey RM, Hans C, Verma A, Sherwani F. Family-centered care to complement care of sick newborns: a randomized controlled trial. *Indian Pediatr*. 2017;54:455–9.
11. Child Health Division, Ministry of Health and Family Welfare, Government of India. Family participatory care for improving newborn health. Operational guidelines for planning and implementation. July 2017. Available at: https://nhm.gov.in/images/pdf/programmes/child-health/guidelines/Family_Participatory_Care_for_Improving_Newborn_Health-Operational_guideline.pdf. Accessed 05 May 2020.
12. Hall SL, Ryan DJ, Beatty J, Grubbs L. Recommendations for peer-to-peer support for NICU parents. *J Perinatol*. 2015;35:S9–13.
13. Kumar H, Kak L. Mother-neonatal intensive care unit - a new model of family participatory care? *Indian Pediatr*. 2019;56:336–7.
14. Maria A, Dasgupta R. Family-centered care for sick newborns: a thumbnail view. *Indian J Community Med*. 2016;41:11–5.
15. India case study on family participatory care: a gateway to nurturing care for small and sick newborn included for launch of nurturing care framework launch for early childhood development at 71st world health assembly May 2018 at Geneva. Available at: <http://nurturing-care.org/wp-content/uploads/2018/05/nurturing-care-case-study-india.pdf>. Accessed 21 May 2020
16. Valizadeh S, Mirlashari J, Navab E, Higman W, Ghorbani F. Fathers: the lost ring in the chain of family-centered care: a phenomenological study in neonatal intensive care units of Iran. *Adv Neonatal Care*. 2018;18:E3–11.

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