

Family integrated care: Supporting parents as primary caregivers in the neonatal intensive care unit

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Received: 7 May, 2021
Accepted: 21 May, 2021

ABSTRACT

Family integrated care (FICare) is a collaborative model of neonatal care which aims to address the negative impacts of the neonatal intensive care unit (NICU) environment by involving parents as equal partners, minimizing separation, and supporting parent-infant closeness. FICare incorporates psychological, educational, communication, and environmental strategies to support parents to cope with the NICU environment and to prepare them to be able to emotionally, cognitively, and physically care for their infant. FICare has been associated with improved infant feeding, growth, and parent wellbeing and self-efficacy; important mediators for long-term improved infant neurodevelopmental and behavioural outcomes. FICare implementation requires multi-disciplinary commitment, staff motivation, and sufficient time for preparation and readiness for change as professionals relinquish power and control to instead develop collaborative partnerships with parents. Successful FICare implementation and culture change have been applied by neonatal teams internationally, using practical approaches suited to their local environments. Strategies such as parent and staff meetings and relational communication help to break down barriers to change by providing space for the co-creation of knowledge, the negotiation of caregiving roles and the development of trusting relationships. The COVID-19 pandemic highlighted the vulnerability within programs supporting parental presence in neonatal units and the profound impacts of parent-infant separation. New technologies and digital innovations can help to mitigate these challenges, and support renewed efforts to embed FICare philosophy and practice in neonatal care during the COVID-19 recovery and beyond.

KEYWORDS

Family integrated care, Neonatal intensive care, Parent-child, Caregivers

Introduction

Family integrated care (FICare) is a transformative model of neonatal care which supports and mentors parents as primary care-givers for their infant in the neonatal intensive care unit (NICU). FICare seeks to directly

address the negative impacts of the NICU environment on infants and their families and puts families at the centre of neonatal care delivery.

In this paper we present the importance of minimizing separation between a parent and infant during NICU

DOI: 10.1002/ped4.12277

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admission and describe strategies to support parent-infant closeness. We describe the components of FICare, review the evidence for this approach, and address FICare implementation including facilitating factors, barriers, and approaches to addressing and sustaining FICare. We conclude by discussing the unprecedented impacts of coronavirus disease 2019 (COVID-19) on parental involvement, and a “call to action” to ensure that post-COVID-19 neonatal care prioritises re-engagement of parents in their infant’s care.

Background

Infants admitted to the NICU are exposed to multiple stressful experiences including painful diagnostic and therapeutic procedures and disruptive environments.¹ Due to their heightened pain sensitivity and immature inhibitory pathways, infants born preterm are particularly sensitive to stressful procedures.² These negative experiences in early life are associated with adverse neurodevelopmental and behavioural outcomes affecting language, motor function, and cognitive abilities into childhood.^{1,3,4} In a study examining whether parent behaviour moderated the relationship between neonatal pain and behaviour at 18 months, preterm infants who received consistent positive and sensitive parent-infant interactions, demonstrated less emotional reactivity, decreased anxiety and depressive symptoms, fewer somatic complaints, and were less withdrawn (avoiding eye contact and being unresponsive to affection) compared to a full-term control group.⁵ Parents are vital in the regulation of stress and development in their infants. Potentially better parent-infant relationships improve the quality of life in families, reducing strain on family functioning, and decreasing family health care utilization.⁶

Impact of parent-infant separation

A key additional stressor in the NICU environment is the physical, emotional and psychological separation of infants from their parents.⁷ Physical and emotional parent-infant closeness is vital for the development of infants born preterm,^{5,8} providing the neurobiological foundation for an infant’s ability to form social bonds and ensure optimal physical, emotional, and mental wellbeing.⁹ As parents interact with their infant, reciprocal interactions between the parent and infant stimulate neurobiological and behavioural processes that support parent and infant well-being¹⁰ and assist the infant’s response to pain and stress.¹¹ In a study by Beebe et al, infants who received frequent touch from their mothers demonstrated better self-regulation and sustained visual engagement with their mother.¹² Parent-infant separation prevents important biophysiological and emotional processes and compromises the development of the parental role, parent-infant relationships, and attachment.⁷

Strategies to support parent-infant interactions

Interventions in the neonatal environment to support parent-infant interactions include: 1) strategies to support parents, 2) parent-delivered interventions, and 3) parent-partnered neonatal care.¹³ Strategies to support parents are focused on helping the parent cope with the NICU experience and equipping them emotionally, cognitively, and physically care for their infant.¹³ Parent-delivered interventions include psychological, educational, communication, and environmental support focused on improving infant outcomes and involve infant care tasks directly performed by the parent such as infant massage or singing/reading to their infant.¹³ Parent-partnered interventions integrate parents as full partners in care at all levels – direct care providers, decision-makers, NICU leadership, hospital administration, and the health care system.¹³

Family integrated care

FICare comprises a comprehensive framework to implement a family centered care philosophy by bringing parents, medical and nursing staff together to develop a collaborative program of education and support; combining the strategies to support parent-infant interactions and highlighting the need for administration and infrastructure support. FICare promotes parental involvement and takes this to a new level by actively supporting parents as primary caregivers and equal partners in the care team.

FICare uses a strength-based approach that focuses on the promotion of parent engagement and the development of parent self-efficacy. It shifts the paradigm of care so that neonatal staff provide education, mentorship, and coaching that focuses on the parent-infant dyad, where parents and infants are considered mutually dependent.¹⁴ The practical model of FICare developed by O’Brien et al¹⁵ in Toronto supports parents in building core constructs of self-efficacy (performance accomplishments, vicarious experiences, verbal encouragement, emotional support) through the use of four pillars (Figure 1).

Evidence supporting FICare

Benefits in the neonatal period

Studies of the FICare model of parent engagement have consistently been associated with improved infant feeding, growth, parent mental wellbeing, and have shown this model to be a safe, adaptable, and feasible. The first FICare pilot study, investigating the model developed in Toronto, requested parents to be present at the bedside providing infant care for a minimum of eight hours a day, attend education sessions for three weeks, and participate in daily medical rounds.¹⁵ This was followed by an international multi-centre, cluster randomized control trial (cRCT) of FICare in 26 Canadian and Australian NICUs,

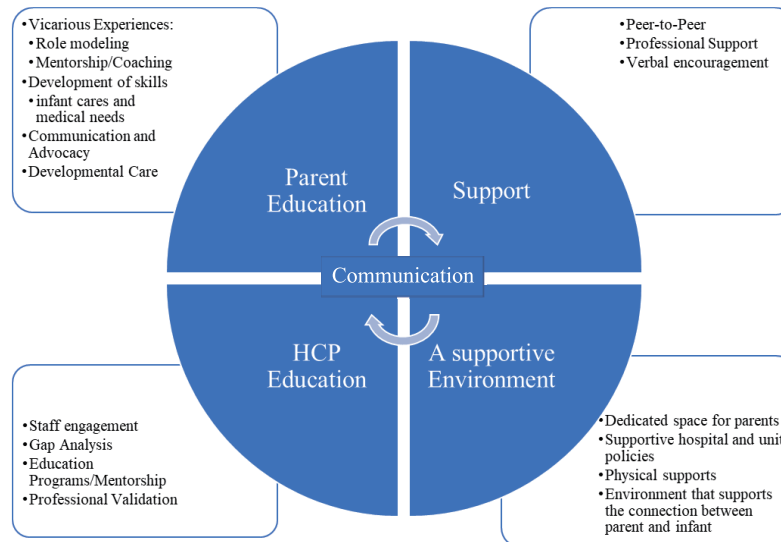


FIGURE 1 Family integrated care implementation. HCP, health care provider.

in which parents actively engaged in infant care for six hours a day.¹⁴ Both studies demonstrated that FICare was associated with improved infant weight gain, infant breast-milk feeding, and reduced parental stress and anxiety.¹⁴

These same benefits were recently confirmed in an RCT of FICare in 11 Chinese NICUs involving 601 preterm infants. Hei et al additionally observed a primary benefit of reduced length of stay and secondary benefits of faster establishment of suck feeds, reduced oxygen requirements, nosocomial infection, antibiotic use, rehospitalisation, and a decrease in health care related costs.¹⁶ In a pre-post intervention analysis in the UK, Banerjee et al demonstrated similar benefits, the establishment of earlier enteral and suck feeds and a significantly reduced length of stay.¹⁷ Similarly, a study in the Netherlands involving 1046 infants receiving FICare in single rooms showed lower infection rates, more exclusive breastfeeding and a reduced length of stay.¹⁸

In a pre-post intervention study, He et al investigated the effects of FICare specifically for infants diagnosed with bronchopulmonary dysplasia (BPD) when parents were engaged in care for a minimum of three hours a day.¹⁹ Results demonstrated a significant decrease in the amount of respiratory support required, and a non-significant decrease in parent expenses during the NICU admission.¹⁹ Oxygen requirements were not significantly affected but FICare contributed to an overall decrease in cost associated with medical interventions.¹⁹

Long-term benefits

Accordingly, it has been hypothesized that the established short-term benefits of FICare on parental stress and anxiety and self-efficacy and infant growth, may be important mediators for improved long-term neurodevelopmental

outcomes and behaviour. A recent follow-up study of a subgroup of infants who participated in the FICare cRCT, at 18–21 months corrected age, demonstrated that infants who received FICare during the neonatal period had a better ability to self-regulate, indicating fewer challenges with sleeping, eating, sensory sensitivity, and decreased negative emotionality.²⁰ In addition, parents perceived that infants who experienced FICare were less demanding, less difficult, more adaptable in social situations, and identified more positive moods and fewer episodes of hyperactivity and impulsiveness. This demonstrates that parental stress related to parenting and parent perceptions of their child are important long term FICare benefits.²⁰ Further analysis suggested that this decrease in parent stress is itself a mediator of the impact of FICare on child behaviour.

Implementing FICare

FICare is change in culture

Changing the culture of care requires neonatal professionals to relinquish power and control, and to instead develop collaborative partnerships with parents. At the centre of this approach is a change in attitudes and behaviour focused on communicating better with parents, seeing parents as primary caregivers, and the neonatal team, especially nursing staff, adopting roles as mentors, educators, and supporters.^{21,22}

Healthcare professional communication is a key component of this change in culture.²³ It has several functions which include building/maintaining relationships, exchanging information, (sharing) decision-making, and enabling parent self-management.²⁴ With good parent-provider communication, parents' experiences within the NICU setting can be ameliorated. Sensitive and appropriate language is needed to build partnerships and support

parents during hospital stay.^{24,25}

Implementing FICare requires that this change in culture is motivated by both health care providers and the health care system believing in the importance of involving parents in care as equal partners, minimizing parent-infant separation, and supporting parent-infant closeness.²⁵

Toivonen et al highlighted the key factors for changing culture as; a multi-disciplinary commitment, staff motivation, timing, and sufficient time for preparation and readiness for change.²⁶ Recognition of the need for change within the wider healthcare system is also crucial as administrative support is required.²⁵ Maintenance of parent and staff motivation is also key, aided by demonstration of observable benefits within their own neonatal units and examples from other neonatal teams.²⁷ Staff may vary in their initial readiness to accept and implement this change in culture and to adopt the FICare model.²⁸ This issue needs to be recognised and addressed as part of implementation in all environments. In a recent survey of neonatal medical and nursing staff in five Chinese NICUs by Xiang et al, prior to education about FICare, over 50% felt that FICare was necessary, but less than 20% felt it was feasible, and 40% felt sure that that parents would not engage with the FICare model.²⁹ However, after a brief education session and group-discussion staff were more positive about both the need for FICare, the feasibility of implementation, and the potential benefits.²⁹ Providing time for preparation and supporting readiness for change through education is an essential component for culture change.

Developing partnerships with parents

Staff developing a partnership with parents is key to the successful implementation of FICare. Brødsgaard et al have identified two key themes for developing positive partnerships between neonatal staff and parents³⁰; 1) the co-creation of mutual knowledge based on respect, trust and sharing of knowledge, and 2) the development of competencies and negotiated roles, supported by space to learn, encouragement, and enablement.³⁰ Relational communication is a tool used by bedside nurses to negotiate caregiving roles as parents gain confidence in providing infant care.³¹ Parents are coached and mentored by health care providers to share information related to their infant's care needs and are empowered to actively participate in rounds and grow their advocacy skills over time.²⁵ Parent-infant closeness is supported by the development of these collaborative partnerships as parents develop trusting relationships with health care providers.³² The Close Collaboration with Parents, is an 18-month theoretical and hands-on education program for the entire multi-disciplinary neonatal team, uses experienced facilitators and local mentors to support nurses in the development of this partnership and has been shown to be a very effective program of improving staff skills.^{22,32}

The strategies outlined above have been applied by neonatal teams internationally to successfully implement FICare, using practical approaches suited to their local environments and resources (Table 1).

Sustaining FICare

Challenges to sustaining FICare

The COVID-19 pandemic highlighted the vulnerability within programs supporting parental presence in neonatal units. As hospitals attempted to decrease the risk of exposure to patients, policies limiting parent access were implemented; creating adverse effects on delivery of neonatal care, and outcomes for infants and families.³⁶ Despite longstanding public pledges by healthcare organizations to deliver family-centered care, often they did not involve families in the development of COVID-19 pandemic response plans.³⁷

Many NICUs restricted parental access to one parent (usually the mother) and, depending on the region or clinical circumstances, significantly restricted the amount of time parents could spend with their infant (sometimes as low as 5–15 minutes per day).³⁷ The one-parent policy left fathers/partners unable to see their infant, often for many of weeks. A recent systematic review found that due to the pandemic, significant changes in neonatal unit policies and restricting parents' access and participation in neonatal care were present.³⁶ Preliminary data suggest that this negatively impacted breastfeeding, parental bonding, participation in caregiving, parental mental health and staff stress. No nosocomial COVID-19 infections were reported within neonatal care, whereas the collateral damage of parent-infant separation in this vulnerable population seems to be large.

Technological approaches to support FICare

New technologies and digital innovations can support FICare implementation and facilitate program sustainment during the challenges of COVID-19. Mobile health apps (mHealth apps) may be potentially effective and convenient means of sharing generic and specific information with NICU parents about their baby's condition and care on their smartphone. Richardson et al recently identified and rated 49 English language apps for NICU parents, but over two thirds of these were considered to have credibility issues, and only 25% were of good quality.^{37,38}

The Integrated Family Delivered Care Mobile App, developed at Imperial College, London in conjunction with patient families, incorporates non-interactive educational components, parent notes and timelines. Use of the app was associated with improved family involvement and outcomes.¹⁷ Franck et al³⁹ are currently performing a clinical trial to investigate the impact of an interactive

TABLE 1 Practical models to support culture change and partnership with parents

| Implementation site | Strategies to support culture change and the development of partnership with parents |
|---|---|
| Family Integrated Care (FICare) Canada, Australia, New Zealand (O'Brien et al ³³) | <ul style="list-style-type: none"> • Structured education program to 1) learn the benefits of parental presence; 2) understand the NICU parent experience; 3) provide resources and skills to support parent collaboration in care • Central steering committee with parent representation • Local site implementation teams with parent representation • Steering committee site visits to support site implementation team and to assure fidelity • Strong veteran parents and peer-to-peer support • Veteran parents involved in all staff education |
| The Close Collaboration with Parents Turku, Finland (Axelin et al ^{22,32}) | <ul style="list-style-type: none"> • Evidence-based educational program for staff supporting parent-infant closeness (close collaboration with parent program) • Theoretical and hands-on teaching to the entire multi-disciplinary neonatal team over 18-month period • Promotion of the development of active listening skills and using joint observations of infant behavior to collaborate with parents |
| Helping US Grow (HUGG) Model of FICare Glasgow, UK (Patel et al ³⁴) | <ul style="list-style-type: none"> • Staff and families are empowered to lead change from the ground up including improved environment, educational resources, opportunities for peer-to-peer support, and communication tools – Helping Us Grow (HUGG) • Staff and Families meet regularly to share experiences, co-create ideas to support family involvement (HUGG meetings) • External support from partnerships with parent organisations, local charities and senior sponsors in organisation |
| FICare Alberta, Canada (Benzies ³⁵) | <ul style="list-style-type: none"> • Partnership between a core project team, scale and spread committee, and local site implementation teams • FICare champions chosen from unit staff • Relational communication used to negotiate roles between staff and parents • Rapid feedback of generated evidence to support adoption |
| Integrated Family Delivered Care (IFDC) London, UK (Banerjee et al ¹⁷) | <ul style="list-style-type: none"> • Care bundle developed to support parent involvement in care, co-designed with veteran parents (IFDC) • Staff training module and “bite-size” bedside teaching • IFDC facilitator supports parent education and support in addition to the bedside nursing staff • Free mobile App for parents provides educational material and diary function |

FICare mHealth app (We3health™) to supplement the delivery of a FICare program and serve as a data collection tool. Video technology has also been investigated to connect families and to support communication with clinical teams. Live video communication from the NICU to parents' devices has been described using both generic video conferencing services (e.g., FaceTime, Skype) and services designed specifically for the NICU environment. NICU staff and parents have reported positive impacts on communication and parental emotional wellbeing,⁴⁰ but with increased anxiety for some parents and increased workload for staff.⁴¹

Short, recorded videos of infants shared with parents from the NICU may address some of these challenges. Kirolos et al recently reported use of a secure asynchronous video service in UK NICUs, which was associated with parental perception of reduced anxiety, increased involvement in care and connection with the NICU staff, supporting FICare models of care.⁴² These technologies may be useful and important components of FICare strategy, but they should not detract from the fundamental priority and benefits of parent presence, direct physical parent-infant contact, and parental involvement in NICU care.

Conclusion

FICare is a practical, evidence-based approach to

supporting parents as primary caregivers in the NICU, for which there is now compelling evidence of benefit for infants, their families, and healthcare services from diverse international settings. Implementing FICare requires multi-disciplinary commitment, motivation, and sufficient time for preparation and readiness. During this process of culture change professionals actively shift the focus of care to provide mentorship and coaching to facilitate the development of partnerships with parents as they gain the skills and confidence to care for their infants.

COVID-19 has starkly demonstrated the negative impact of parent-infant separation in the NICU. In response The International FICare Steering Committee has developed recommendations highlighting the urgent, universal need to support all parents to be present continuously, routinely leading and participating in neonatal care and decision making for their child.³⁶

CONFLICT OF INTEREST

None.

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SUPPORTING INFORMATION

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How to cite this article: Waddington C, van Veenendaal NR, O'Brien K, Patel N. Family integrated care: Supporting parents as primary caregivers in the neonatal intensive care unit. *Pediatr Investig.* 2021;5:148-154. <https://doi.org/10.1002/ped4.12277>