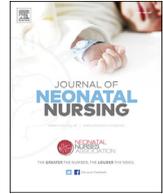




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Family centred care and family delivered care – What are we talking about?



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ABSTRACT

Family centred care (FCC) is an integral part of high quality neonatal care in developed countries. More recently, family integrated care (FIC) is increasingly becoming a more popular model of care delivery in neonatal units. We strongly believe that FIC is the voice of the modern family in the neonatal unit and will provide significant benefit not only in terms of infant medical outcomes, but will also reduce stress, anxiety and depression in the family; improve their ability to cope and through structured competency based educational programmes will result in true partnership with parents. In this article we have discussed the historical perspective and recent evidence around FIC and compared this with FCC. We have also discussed the basic principles of FIC and then compared the various existing professional and parent focused neonatal care programmes and the advantages of FIC over those traditional models of care.

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1. Introduction

Over the last few decades advances in neonatal care have pushed down the age of viability resulting in the survival of more extremely preterm infants. Although childbirth is a great leveller in life (Chalmers, 2013), the birth of a preterm infant can fill the parents with significant anxiety and stress compared to term arrivals (Lau and Morse, 1998). In the highly technological environment managed by trained healthcare professionals in the neonatal intensive care unit (NICU) the parents are physically, psychologically and emotionally separated from their infants in a situation when a new family is about to bond. The parents may experience fear because of the incredible situation of a premature infant arriving early, have their hopes and dreams shattered, they may blame themselves for the situation and experience intense guilt and anger (Flacking et al., 2012; Woodward et al., 2014).

Parents can also feel they don't have a role in the neonatal unit while the baby requires intensive care as their loved one is looked after by the specialised healthcare professionals. Once the mother is discharged home, the parents can find it extremely difficult to cope coming to the hospital regularly to see their infant in the NICU and managing their life with other siblings and travel (Stjernqvist,

1992). They may doubt their ability to care for their infant who they find difficult to bond with; hence, it is not surprising that the mothers of preterm infants experience significantly higher rates of depression when compared to their term peers (Veddivi et al., 2001). Also nearer the time of discharge home from a medicalised intensive well monitored environment to a home setting with no monitoring or trained healthcare professionals, parents find it extremely challenging and difficult to cope. Home support programmes have been shown to reduce stress and anxiety but not impacted on maternal coping (Brett et al., 2011).

The setting of the NICUs in the Western world have changed over the last decades influenced by evidence emerging initially from the Indian subcontinent and Eastern European countries such as Estonia. In those countries a lack of trained healthcare professionals resulted in bringing the mothers to the cotside and supporting them to look after their infants. This resulted in reduced mortality (Daga and Shinde, 1987; Karan and Rao, 1983), mortality from neonatal infections (Mohan and Karan, 1986), less use of antibiotics, better breast-feeding rate (Karan and Rao, 1983), improved weight gain (Karan and Rao, 1983) and earlier discharge home (Karan and Rao, 1983; Bhutta et al., 2004) and reduced re-admission rates (Bhutta et al., 2004; Bastani et al., 2015). A pilot study from Tallinn, Estonia showed these improved infant outcomes of as reduced neonatal infection, improved weight gain and breast-feeding rate (Levin, 1994). These studies also reported better parent experience, confidence and reduced anxiety (Bastani et al., 2015).

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While the western world with the technological advances and machines around the cotside was pushing the parents further away from their infants, the lack of provision of highly sophisticated medical care and lack of trained healthcare professionals was bringing the parents and infants closer in the neonatal units of the East. However, during the latter half of 1980s there was a realisation in the West that for better neurodevelopmental outcomes early interventions and a humane approach is necessary. This has led to development of structured programmes such as Neonatal Individualised Development Care Programme (NIDCAP) (Als et al., 1986), Mother Infant transaction (MITP) programme (Rauh et al., 1990) and Creating Opportunities for Parent Empowerment (COPE) programme (Melnyk et al., 2006). The main precept of these programmes is to support parents either by educational interventions or care-by-parents model or professional focussed support of the infant with developmental care programme.

2. Family centred care

Family centred care (FCC) is increasingly becoming integral component to the provision of optimum neonatal care. There is an ever-increasing list of professional organisations that are providing guidelines integrating family centred care principles into their standard practices (Committee on Hospital Care, 2003; Davidson et al., 2007; Lewandowski and Tessler, 2003). FCC is characterised by some core principles; the family is treated with dignity and respect, healthcare providers share unbiased information with parents in a way that is accessible, parents build on their strengths through participation of various experiences that enhances control and independence as well as involving parents in policy and programme development around delivery of care (Johnson, 2000). The parents of preterm babies (POPPY) project in UK has shown that irrespective of the level of care, considerable variability exists in provision of family centeredness between the neonatal units (Redshaw et al., 2010). Although research has shown that by involving parents and giving them their parent identity (Wigert et al., 2010) bonding is promoted, and involving them in decision making enhances their confidence in preparation for discharge (Dellenmark-Blom and Wigert, 2014; Franck and Axelin, 2013). However, many neonatal units in the UK are lagging behind in providing them with an optimum environment and space and nurturing this relationship (Redshaw et al., 2010). FCC involves 24/7 access to parents and families as well as siblings to develop the loving bonding relationship with their infant. They are given regular updates by the healthcare professionals and encouraged to be present in the ward rounds.

Many neonatal units do not favour parents of other infants to be present in the ward round citing various reasons, such as, they may be discussing sensitive confidential information and hence mothers remain separated from their infants during the ward rounds and handovers which can be upto 4–6 h in a day. This separation can be easily eradicated in an innovative way by providing the parents with a sound blocking headphone. Our group have reported reduction of separation time and parental satisfaction following introduction of headphones during handovers and ward rounds (Deierl et al., 2015). FCC encourages parents to participate in daily cares for their infants such as oral/mouth cares, nappy change, tube feeding, breast feeding and skin-to-skin care at cotside. Parents are offered information through routine updates by healthcare professionals and providing them with parent information leaflets. FCC encourages parents to stay in the neonatal units as long as possible and hence there is an obligation to provide them with kitchen, family accommodation, car parking and easily accessible food. Parents should also be provided with comfortable chairs at cotside to enable them to have long and settled skin-to-skin sessions and

breastfeed their infants. FCC involves providing the parents with adequate psychological support to help with their stress and anxiety around the care of their vulnerable babies. Medical professionals historically were trained to make decisions around neonatal care in a paternalistic way (Aarthus and Akerjordet, 2014). Latour et al. (2010) reported that nurses are more oriented towards work organisation and professional attitudes and less towards parents' information needs and participation. Despite this, the nurses have more positive attitudes about the FCC philosophy, even when there is significant difficulty in practice because of organisational and environmental conditions (Coynne et al., 2013).

The Bliss Baby Charter published in 2005 provides the core principles to standardise FCC across the UK thereby advocating FCC as one of the best practices of care in the neonatal units across the UK (Bliss, 2011. **The Bliss Baby Charter Standards.** <http://www.bliss.org.uk>). Units are encouraged to participate in this accreditation process to work towards FCC and to identify weaknesses and barriers and improve practice to meet the standards.

3. Family delivered or integrated care

Family integrated care (FIC) or family delivered care (FDC) involves providing parents and carers with sufficient education and tools so that they are able to become confident and independent primary carers of their infants under the team's supervision. In order for FIC to become the standard of care within a neonatal unit the basic principles of FCC should already be in place. FIC is a step further to FCC as here the parents become integrated as equal partners in the neonatal team. Some of the basic differences between FCC and FIC are demonstrated in Table 1.

FIC is a paradigm shift from the current standard of care practiced around the neonatal units in UK. Parents are empowered to become equal partners in the team caring for their infants in collaboration with medical, nursing and allied health professionals. They present their baby's condition in ward rounds and discuss management plans with the team. They are listened and joint decisions are reached. Nurses become teachers and facilitators from the role of a do'er. Parents subsequently gain knowledge, confidence and control through intensive competency based training as part of the FIC programme. Parents assume most of the care of their medically stable infants except intravenous medications, respiratory support and investigations.

The FIC programme is primarily based on four basic principles as highlighted by Lee and O'Brien in their pilot RCT (O'Brien et al., 2013) and the following multicentre block randomised trial across Canada, Australia and New Zealand (O'Brien et al., 2015). Their programme has become an aspiration for our team and formal collaboration has been built with the team at Mt Sinai hospital.

The *first principle* is parents form part of the care team looking after their infants to the best of their abilities, and they are treated with respect and dignity as equal members. In many ways this requires a change in culture shift within the neonatal team.

The *second principle* is providing them with education, knowledge and tools to facilitate their understanding of neonatal care required for their infant. This can be in the form of one to one education at cotside, group education or by giving consistent written/electronic information. In our Quality Improvement initiative called Integrated Family Delivered Care (IFDC) our team chose to develop a mobile application created by our group called Imperial IFDC Neonatal app. Such teaching materials can be developed locally, or obtained from units already advanced in FIC. The FIC website of Mt Sinai hospital contains valuable information and material for the implementation of this care model. The Imperial IFDC App can be downloaded internationally from the Apple

Table 1
Basic differences between family centred and family integrated care.

| | Family-Centred Care | Family-Integrated care |
|--------------------------|---|---|
| Staff Education | Staff training offered around Family-centred care in medical and nursing schools, NHS and charities. | Structured training empowers health professionals to be coaches, mentors and counsellors for parents. Clear training syllabus for staff. |
| Parent Education | Information offered by the neonatal unit staff and self-identified by parents. Inconsistent and varied. | Formal training delivered by NNU staff/veteran parents. Clear training curriculum and competency assessment for parents |
| Parent visiting policy | Encouraged to be present on the unit as much as possible. Facilities in place to support this (kitchen, family room, accommodation) | Encouraged to be present on the unit for at least 6–8 h per day and assume most of the primary care of their baby. Facilities in place to support this (kitchen, family room, accommodation for every parent) |
| Routine Cares | Parents are encouraged to be involved in routine daily cares for their baby (feeding and changing). | Parents are encouraged to be involved in daily and enhanced cares for their baby with a level of autonomy following a competency-based training. |
| Medical Rounds | Parents are encouraged to be present for the ward round may be asked questions about their baby | Parents are encouraged to be active members of the ward round and present their baby to the health professionals |
| Administering medication | General understanding of the medication given to their baby. | Identify the purpose of routine medication. Administer approved oral medication under supervision of nursing staff |
| Psychosocial Support | Availability of psychosocial support. | Availability of psychosocial support and peer support from trained veteran parents |

Appstore (<https://itunes.apple.com/gb/app/integrated-family-delivered-neonatal-care-ifdc/id1196284490?mt=8>) for iOS devices and Google Playstore (<https://play.google.com/store/apps/details?id=com.neonatal>) for Android devices.

The *third principle* is integrating parents to all aspects of neonatal care. Presentation in the ward round as much as possible even saying the name, the birthweight and the gestation of their babies gives them confidence to be able to understand and discuss care with healthcare professionals. Ward round proforma are useful tools for parents to have a prompt sheet during ward rounds and our group has produced a proforma adapted from the FICare programme at Mt Sinai hospital. This proforma is now endorsed and presented as best practice both by Bliss and the London Operational Delivery Network.

The *fourth principle* is that the entire team from medical, nursing to the allied health team should support this model of care. The unit policies and environment should support parents having skin-to-skin care and breastfeeding at the bedside, support the parents to stay as long as possible at the cotside and provide them with travel, parking facilities and care for food and drinks for the parents. One of the other requirements of FIC is facilitating the staff with education and tools in communication through FIC modules within the neonatal mandatory training programmes for medical and nursing staff. In our group we facilitate nursing staff through one-to-one teaching and group teaching sessions.

FIC does not stop after discharge from the neonatal unit. The majority of the FIC programmes provide discharge planning teaching sessions aiding the parents about life after discharge from the neonatal unit including basic life support training. Some also offer follow up group sessions covering a range of topics to support the development of the infant and parent journey. In our neonatal unit, this is facilitated by the discharge liaison team, developmental care specialists, psychologists and speech therapists and breastfeeding consultants. Parents are informed prior to each teaching sessions about the topics; we run a rolling programme of about 7 topics over a 4–5-month period. After sometime the parents from these groups may join the FIC programme as veteran parents. Their role is to offer peer support and participate in the further development of the FIC programme.

4. Early intervention programmes for preterm infants and their parents

Various models of early intervention have been developed over the years to promote FCC in North America (Gooding et al., 2011)

such as the Family centred care map, the March of Dimes and COPE, including programmes supported by American Academy of Paediatrics and Vermont Oxford Collaborative. These programmes are generally focussed into three major fields: parental educational intervention, care-by-parents model and healthcare professionals focussed model. Some programmes such as COPE focused on parental education and behavioural intervention and have shown improvement in infant and parent outcomes (Melnyk et al., 2006). One of the limitations of this trial was the parents received a structured educational-behavioural programme but they did not get involved in daily care giving activities. Another study used a skill-based programme called ‘cues’ but failed to demonstrate any measurable benefit over non-specific education (Zelkowitz et al., 2011). The care-by-parents models such as reported by Levin (1994) and Ortenstrand et al. (2010), required parents to be present in the cotside providing care for their infants 24 h a day, but did not specify a structured educational programme for them. Nevertheless, both models showed significant benefit in infant outcomes such as reducing length of stay in the neonatal unit, reduction of neonatal infections and a decrease in moderate bronchopulmonary dysplasia in preterm infants.

The synactive theory of neurobehavioral development, introduced by Als in 1970s form the basic principles of NIDCAP. It requires trained and certified caregivers to use the NIDCAP assessment. It is labour intensive as well as expensive both to implement and to maintain as it requires developmental specialists, regular NIDCAP assessments and training of healthcare professionals. A systematic review and meta-analysis of literature (Ohlsson and Jacobs, 2013) involving 627 preterm infants demonstrated that NIDCAP neither improve any short-term infant outcomes nor long term neurodevelopmental outcome. The composite outcome of death or major sensorineural disability at 18 months of corrected age or alter in childhood did not differ significantly between the two groups. There was no difference in hospital deaths, BPD at 36 weeks, intra-ventricular haemorrhage (IVH), sepsis, retinopathy of prematurity (ROP) and necrotising enterocolitis (NEC). Although the Bayley scales of mental development index (MDI) favoured NIDCAP at 9 months of corrected age, there were no differences at 12 and 18 months of corrected age. Glazebrook et al. used a nurse led programme to support parents in a RCT across 6 centres in UK and were unable to demonstrate any significant changes in parent or infant outcomes (Glazebrook et al., 2007).

None of these programmes focussed on a team approach to education and they were more focused on structured training of healthcare professionals. Hence the effect of the programme

although started early stopped with hospital discharge. A few studies have tried to address the lack of support following discharge home by providing telephone support and video conferencing or home visits by trained healthcare professionals, unfortunately these supports were all short term and sporadic and mainly focussed on a smooth transition home. Larger trials such as Infant Health and Development Programme (IHDP) (Enhancing the outcomes of, 1990) and the Avon Premature Infant Project (APIP) (Randomised trial of paren, 1998) provided early parental education and developmental intervention by trained healthcare workers; both failed to report any beneficial effect beyond the intervention period.

Compared to all such programmes and care models, the FiCare programme piloted in Mt Sinai hospital at Toronto, Canada was experience co-designed by a multidisciplinary steering committee that included veteran parents, physicians, nurses, parent educator, lactation consultant and a social worker. The principles of the programme were based on the four core principles described earlier. The pilot study reported it to be safe, feasible and resulted in improved weight gain among preterm infants. The subsequent RCT has also shown improved weight gain and breast-feeding rate as well as reduced parental stress and anxiety. Initial report from a RCT using FIC model in China has shown significant improvement in neurodevelopment at 18 months of corrected age using Bayley III assessment scale (Hei et al., 2016). FIC programmes are feasible, do not come with additional costs, parent focussed and will improve infant and parental outcomes; the principles of care are directed towards parents taking the ownership of their infants which will impart confidence and independence to the families resulting in better long-term outcomes in the preterm infants.

5. Summary

Family centred care (FCC) has become an integral part of providing high quality neonatal care in the developed countries. The Bliss Baby Charter provides the core principles to standardise FCC and thereby advocating FCC as one of the best practices of care in the neonatal units across the UK. Family integrated care (FIC) or family delivered care (FDC) involves providing parents and carers with competency based training and tools so that they are able to become confident and independent primary carers of their infants under the team's supervision. FIC is a step further to FCC as here the parents become integrated as equal partners in the neonatal team. Compared to other early support and discharge programmes FIC provides the parents with training, education and support which enables them to be primary carers and gives them confidence, knowledge and independence to take care of their infants while in the neonatal unit and post discharge who may have complex medical needs. Although results from neurodevelopmental outcomes from large RCTs are awaited, it is anticipated that these FIC programmes may have more long-lasting benefits than professional focussed programmes used in the past to support the infants.

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