Family-integrated care in the neonatal unit

Family-centred care has been shown to benefit outcome for the neonatal patient but translation into practice is poor. An innovative model of care, family-integrated care (FIC), was piloted in Canada with promising results. This model has been adapted and introduced into the Leeds neonatal service. This article discusses the background to FIC and the methods used to set up the model in Leeds.

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Keywords

family-integrated care; family-centred care; quality improvement; breastfeeding

Key points

McKechnie L. Family-integrated care in the neonatal unit. *Infant* 2016; 12(3): 79-81.

1. Having a newborn infant in the neonatal unit is stressful and disrupts the normal parenting role with potential long-term consequences.
2. Providing education and coaching empowers parents to become the centre of their baby's care.
3. Developing an integrated care model has significant positive outcomes for infants and their families.
4. Changing neonatal care from a traditional model to an innovative, family-integrated model is challenging for staff.

Preterm delivery is a very stressful time for a family and for their newborn infant. This has been increasingly recognised in recent years and interventions to improve have been developed and tested. Family-centred care (FCC) is one such initiative and this has been shown to benefit patient health, parent satisfaction and the quality of health care.[1] Readmission to hospital is also decreased in infants who have had a FCC approach to their neonatal care.[2]

FCC is widely defined as a partnership approach to healthcare decision-making between the family and the healthcare provider. Widening the definition, FCC is about recognising the integral role the family play in a child's physical, social and emotional growth and development.

Background

A mother and her baby are inextricably linked and to separate the two would seem counterintuitive. However, Western health care has evolved in this way with physician as authoritarian, nurses as gatekeeper to the infant and families as bystanders.[3] Many parents report feeling isolated and detached from their baby; 'voyeurs' to their infant's care. The newborn infant, at a most vulnerable time, is removed from its mother and often is not held by her, does not feel her touch or hear her voice again for hours or days. After several weeks of intermittent physical contact, enormous stress and multiple painful interventions the mother and baby are sent out into the world together and expected to flourish, largely on their own.

Gradually neonatal practitioners are beginning to accept that this is not an ideal way to deliver health care, however, there remains a great divide between the talk about FCC and what actually happens in practice. There are misunderstandings and ignorance about what FCC really is and as such, true FCC is not delivered.[4] FCC is most effective when families are engaged in open and honest communication with the care providers and when their care adapts to the family's cultural, social and ethical beliefs. Hence, FCC requires an entire culture shift that enables the family to move into the spotlight at the centre of their infant's care. Each and every member of the team is integral to the delivery of FCC. A recent study[5] emphasises how much parents value being involved in their baby's care, the challenges of expressing breast milk, communication, information and relationships with staff, all of which highlight the importance of practising true FCC.

Recognising these underlying principles, many interventions have been developed over the years to enable effective partnership between parents and healthcare providers. Staff training and education enables better communication between professional groups and with families. Modern neonatal units are designed to better accommodate the family's needs as well as those of the service. Education programmes, support groups and online support tools have all been developed to help improve the journey from birth to discharge and beyond.

Individually many of these interventions have been shown to have some successes in outcomes for the infant and/or the family. However, the practices have not been widely adapted and the barriers to this are poorly understood.[4] There are few large scale randomised controlled trials to

support most FCC practices and there are gaps in the research regarding it. Two important interventions have been reported recently. Firstly, the NeoPAss programme in Germany – a multi-professional pathway for family-integrated care (FIC) that began in 2012.[6] The programme has enabled many important benefits for babies and their families including better breastfeeding rates, shorter length of stay and fewer complications of prematurity, for example infection.

FIC in Canada

A second recent innovative approach to delivering neonatal care involving FIC has been recently reported from a neonatal unit in Toronto, Canada. This has been received with great enthusiasm across many countries and is currently being evaluated by a randomised controlled trial in North America, Australia and New Zealand.

FIC is based on a healthcare model in a lower resource setting (Estonia) that uses its sparse neonatal nursing workforce in a very different way to conventional Western health care. The framework of this model was taken back to the tertiary neonatal setting in Canada. It has been adapted to be a model of care where the nurses, through education, coaching and mentoring support the parents to become the primary caregivers in their infant's journey through neonatal care (**FIGURE 1**).

The pilot study[8] included 42 mothers and their infants. Enrolled infants were ≤35 weeks' gestation and receiving continuous positive airways pressure (CPAP) or less, as respiratory support. They were receiving at least 50% of their feeds enterally. Parents were asked to spend at least eight hours a day with their infant and attend ward rounds and a daily education session. They each completed a 'parental stress scale' questionnaire on enrolment and when their infant was 35 weeks' gestation equivalent, if still an in-patient. Parents kept a record of the skills they learnt, such as feeding and bathing, as well as basic charting and medicine administration. Nurses maintained control of more technical aspects of care such as nasogastric tube insertion and manipulation of oxygen delivery.

Their primary outcome was infant weight gain, which was significantly higher than the control group. They also had a marked increase in breastfeeding at discharge (82.1 *vs* 45.5%, p=0.05). Importantly, parental stress was significantly reduced at 35 weeks' gestation among parents on the programme compared to controls. There was a significant improvement in stage 3 or higher retinopathy of prematurity and there were trends towards improvements in nosocomial infection and incident reporting. Numbers were too small to see changes in other complications of prematurity such as necrotising enterocolitis, chronic lung disease and intraventricular haemorrhage.

While the measureable benefits of FIC are encouraging, qualitative feedback was equally impressive. Both staff and parents felt the programme had benefits for both parties. The additional benefit of this programme, in the modern NHS, is that it could potentially be implemented with little additional resource, as demonstrated in the Leeds neonatal service presented here.

On the results of this pilot an international randomised trial has been running since 2013 and should be reporting later this year. Other trials have been set up to evaluate FIC, including FIC in Leeds.

FIC in Leeds

The Leeds Centre for Newborn Care comprises a large tertiary intensive care unit with all specialties including surgery and cardiac services, and a smaller local neonatal unit two miles across the city. Traditional practice has been that families from within the catchment area usually spend the first part of their neonatal stay in the intensive/high dependency unit and, when ready, they graduate to the special care unit, which prepares them for discharge home. The service FCC team decided to develop FIC in the Leeds special care unit as a quality improvement project, with the primary aim of improving rates of breastfeeding at discharge.

The FIC multidisciplinary team consists of two parent volunteers, neonatal nursing staff of all bands, the outreach nursing team, a physiotherapist, occupational therapist, psychology counsellor and a breastfeeding specialist midwife, as well as a consultant neonatologist (the author). The team evolved from one set up when the service first completed the Bliss Baby Charter Audit a couple of years earlier. The nursing team are key to the implementation of FCC or FIC but the old-fashioned hierarchy still prevalent in the NHS means having consultant leadership is essential. Medical buy-in to the FIC programme is also essential to successful implementation of the model of care.

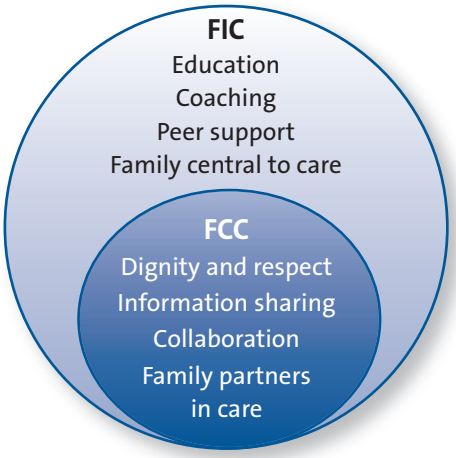

FIGURE 1 The key principles of family-centred care (FCC) as a subset of family-integrated care (FIC).[7]

The Canadian team, with Dr Shoo Lee and his colleague Karel O'Brien, were generous with their time and sharing of the resources they had developed for the programme in their neonatal intensive care unit at Mount Sinai Hospital, Toronto. The Leeds team adapted these for local use and developed an education programme for both staff and parents.

Physical changes to the unit

With the help of a grant from the True Colours Trust and Bliss, the existing local neonatal unit was adapted. The money enabled reallocation of rooms to provide an additional multi-use room for parent teaching, expressing breast milk, etc. The rooms were made more 'family friendly' and more breast pumps and feeding chairs were purchased. Other than this, no additional money was used. Other professionals with interests in key areas have donated advice on psychological support and measurement of health economic variables.

Staff education

The staff education programme was initially planned as a full day workshop to introduce the ethos of the programme and enable staff to learn and ask questions about the proposed model of care and their anxieties. Such is the demand on the neonatal nursing resource that this was reduced to a two-hour teaching session with a lot of one-to-one time during the normal working day. This has been one of the major challenges of introducing FIC to

the service – staff knowledge was not as great as initially hoped. Involving staff more in the implementation of FIC would, perhaps, have brought about the culture change the model requires much sooner.

Staff were concerned when FIC was first discussed. This was also the case in the Canadian experience. Nursing staff felt quite threatened by parents taking over what has traditionally been seen as the nursing role. Some suggested that perhaps this was a way of decreasing nursing numbers as a cost improvement plan. However, as the nurses are key to the education and coaching of parents, it was soon demonstrated that this was not the case. Nursing ratios remain unchanged. In fact, job satisfaction has, anecdotally, been enhanced by creating a successful relationship between the nurse and the mother through education and empowering the parent to be the primary caregiver.

Parent education

The education programme for parents was developed by the multidisciplinary team and delivered daily, Monday to Friday, by a health professional or 'veteran' parent of a preterm infant. There is a three-week rolling programme of sessions every lunchtime, covering a range of topics such as feeding, medical conditions, development, etc. Each session has a core team that can deliver it either on the ward or in the sitting room near the ward. A recent development has been the ability to offer a free meal to one parent (usually the mother) so that they can eat together and use the sessions not only as education but also peer support.

Progress

The Leeds FIC programme has been running for six months and some promising data are beginning to emerge. Breastfeeding rates at discharge are improving alongside infection rates and length of stay. The parents that have gone through the programme report great satisfaction from participating and increased confidence caring for their baby. Interactions the family has with health professionals post-discharge have always been routinely collected by the outreach nursing team, and this data will be evaluated for change. Decreased need for hospital or GP attendance due to improved parental confidence may have long-term benefits to the ongoing care of these infants.

Implementation across the whole service is now the goal as the anecdotal benefits for families and staff are clear. There have been no adverse incidents reported as a consequence of greater parental involvement with care. Given the NHS's current financial state, it is reassuring to report that the implementation of this model of care has not added to costs at all.

However, implementation of the FIC model has not been without its challenges (**TABLE 1**) and there are still hurdles to overcome. The Leeds experience will undoubtedly help other units keen to implement FIC into their service.

Lack of resources	Time	No additional time available for set-up or maintenance of FIC
	Money	Although a low cost intervention, some financial support would enable better implementation
Staff education	Due to poor staffing levels, releasing nurses to study days is difficult but essential for success	
Momentum	Maintaining recruitment to the programme remains a challenge and a dedicated team leader would help	

TABLE 1 The challenges facing successful implementation of family-integrated care in the neonatal unit.

Conclusions

Despite the hurdles, even if all the hard work results in only small improvements in measurable outcomes, the benefit to families is worth it. To have not just one but many mothers tell you that the experience enabled them to feel like a mother for the first time is worth its weight in gold.

References

1. **Committee on Hospital Care.** American Academy of Pediatrics. Family-centered care and the pediatrician's role. *Pediatrics* 2003;112(3 Pt 1):691-97.
2. **Bastani F., Abadi T.A., Haghani H.** Effect of family centred care on improving parent satisfaction and reducing readmission among premature infants. A randomized controlled trial. *J Clin Diagn Res* 2015;9:SC04-08.
3. **Gooding J.S., Cooper L.G. et al.** Family support and family centered care in the neonatal intensive care unit: origins, advances, impact. *Semin Perinatol* 2011;35:20-28.
4. **Kuo D.Z., Houtrow A.J. et al.** Family-centred care: current applications and future directions in pediatric health care. *Matern Child Health J* 2012;16:297-305.
5. **Russell G., Sawyer A. et al.** Parent's views on care of their very premature babies in neonatal intensive care units: a qualitative study. *BMC Pediatrics* 2014;14:230.
6. **Keller M.** NeoPAss, a systematic approach for implementation of family integrated care in the NICU. [Abstract] *Medela 11th International Breastfeeding and Lactation Symposium 2016.* Available from: www.medela.com/breastfeeding-professionals/news-events/congress-2016/abstracts [accessed 3 May 2016].
7. **Institute for Family Centred Care.** *Patient and Family Centred Care Core Concepts.* [Online]. Available from: www.ipfcc.org [accessed 6 April 2016].
8. **O'Brien K., Bracht M., Macdonell K. et al.** A pilot cohort analytic study of family integrated care in a Canadian neonatal intensive care unit. *BMC Pregnancy Childbirth* 2013;13(Suppl1):S12.

Are you interested in setting up family-integrated care in your unit?

To ensure consistency and quality it is important that neonatal services develop similar FIC models that can be easily compared via measurable outcomes. This approach will help to embed FIC as a standard of care and ensure commissioning is appropriate.

A national meeting is proposed; provisionally planned for autumn 2016. Supported by the charity Bliss, interested healthcare professionals can gather together for presentations, workshops and networking to share ideas and help develop FIC more widely.

If you are interested in the possibility of a meeting please email Liz McKechnie (**l.mckechnie@nhs.net**) or Zoe Chivers at Bliss (**zoec@bliss.org.uk**) so that we can gauge interest.