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Integrated family delivered care project: Parent education programme

Karen Platonos*, Annie Aloysius, Jayanta Banerjee, Aniko Deierl

IFDC Core Group, Neonatal Unit, Imperial College Healthcare NHS Trust, Du Cane Road, London, W12 0HS, UK



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ABSTRACT

Parent education is one of the main “pillars” of Family Integrated Care (FIC); therefore it was considered central point in our Integrated Family Delivered Care (IFDC) programme. If parents are to be enabled, empowered to be “experts” in their baby’s care and participate in the care team as equal partners, they will need to receive consistent and high quality information as well as a supportive education programme that has been tailored to meet their needs under their special circumstances in the neonatal unit. As part of the IFDC project, a complex experience co-designed training material was created which consist of several different learning opportunities from chapters in the mobile app, to one-to-one training, competency assessments and small group teaching based on a rolling weekly programme.

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1. Introduction

Having a baby admitted to a neonatal intensive care unit can be a very stressful and highly emotional time for parents. The lack of familiarity with this high tech environment often leaves them at their baby’s cot side feeling powerless, uninformed and an outsider. As they struggle to come to terms with their new role they may find it difficult to feel that they are part of their baby’s journey. Specialist care is delivered by highly skilled doctors and nurses leaving parents with feelings of inadequacy, unable to contribute in any way even with the most basic of tasks. This in turn leads them to feeling isolated and unattached to their infant. Subsequently their ability to form a bond with their baby could be affected and this can impact on their parenting skills and attachment in the future.

Many parents will not know how to access reliable support and advice about their child at this time and this may result in them using the internet to search for what is often unreliable and sometimes quite frightening information. Unable to process what is going on leaves them feeling displaced and deprived by a lack of good communication and sound knowledge. As they struggle to regain some control this may lead them to behave in a way that could be perceived as “challenging” by neonatal staff and can make relationships difficult to manage.

Fortunately, now there is an increasing awareness that the environment of the neonatal unit does not really provide the best conditions to support early relationship building and the

importance of parent involvement and family integrated care is becoming more and more the focus. The neonatal team at Imperial College Healthcare NHS Trust have embraced the principles of family centred care for a long time having an established multi-disciplinary approach to the provision of care. Parent presence is encouraged even during ward rounds, enabled by the use of sound blocking headphones. Parent presentations during ward rounds are advocated. (There is a video example of parents presenting on ward rounds on our Integrated Family Delivered Neonatal Care Project ICHNT Facebook page). Early skin-to-skin is promoted even with our extreme pre-terms as early as possible. We have above national average breastfeeding rates (Fig. 1 and Table 1).

In 2015 we embarked on a Quality Improvement Project which we called “Integrated Family Delivered Care”. We forged links with the Family Integrated Care (FIC) team from Mt Sinai Hospital (Toronto, Canada) and have drawn on their experience when designing our care programme. The Canadian team concluded that parent education was “absolutely necessary” “to enable parents to become true partners in their baby’s care, and that the education component of their FIC programme has proven to be an extremely important cornerstone (Bracht et al., 2013). If parents are to become true “experts” in the provision of their baby’s care, spending long periods of time at the cot-side, taking part in decision making, they need extra support and guidance from the whole neonatal team to do so.

1.1. Models of NICU parent education

When formulating their parent education programme the Canadian team evaluated current literature describing the informal

* Corresponding author.

E-mail address: ifdc@nhs.net (K. Platonos).

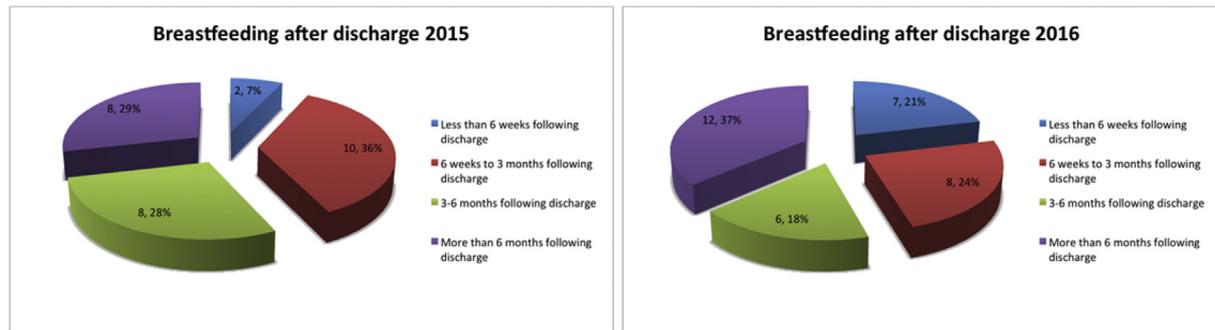


Fig. 1. Breastfeeding after discharge based on the 2015 and 2016 parental survey.

Table 1
NNAP results for question 'Mother's milk at discharge'.

NNAP Questions	2012		2013		2014		2015		2016	
	QCCH	QCCH	SMH	QCCH	SMH	QCCH	QCCH	SMH	QCCH	SMH
What proportion of babies of 33^{+0} weeks gestation at birth were receiving any of their own mother's milk at discharge to home from a neonatal unit?	87%	82%	93%	80%	90%	70%	88%	80%	73%	79%*

need of and approaches to educating NICU parents as well as educational initiatives and formats used to support NICU families: "Parent participation in educational programs that provide information and opportunities for sharing and problem solving has been shown to reduce parental stress and anxiety, as well as improve confidence and competence. The varied program formats and components reported in the literature include single information/support sessions, one to one support, audiotaped and written material, on-going weekly support meetings, individualised psychosocial support and education in specific areas such as breastfeeding, kangaroo care and baby massage" (Bracht et al., 2013).

1.2. Learning styles

Education and teaching is more than just delivering information; it's about getting people interested and excited about what they are learning. It's about finding out what they already know and the experience they may already have; it's about building a relationship of trust with those who wish to learn and helping them to continue to learn beyond the even after the education has finished. We all learn and retain information in different ways. So when planning an education programme it is important to take these differing learning styles in to account. Some people will be happy to sit through a lecture where learning is facilitated by listening but it is not the only way that everyone prefers to learn. Others will remember visual images better than spoken information and find photos and pictures useful. Some people prefer to learn by discussing questions within a group and working together to problem solve. Others learn by practical "hands-on" demonstration, remembering things they have already done. Within any group there will be people with different learning styles and needs, in the same way different topics will require different teaching methods, so it is good to use a variety of teaching styles and methods to help learners and build several methods into any one teaching session. Furthermore it is important to keep in mind the way in which a parent with a sick child on a neonatal unit may process or gather that information and that the process could well change according to the course of the child's journey so the teacher may well need to adapt the way that the information is presented to meet the parents' specific needs at that time.

1.3. IFDC parent education material and mobile parent app

Over the past two years our team of neonatal health professionals made up of members of the multidisciplinary team, doctors, nurses and veteran parents have created an experience co-designed competency based training material for parents.

The parent education curriculum consists of 15 chapters, a developmental timeline, glossary of medical terms and links to other additional support resources. The interactive section of the App includes a diary function where parents can record skin-to-skin cuddles, expressing, feeding, growth and memories of their journey.

In order to be easily accessible and wanting to use up to date technology we have combined all of our materials in to a mobile educational App (Fig. 2). As Imperial Health Charity funded the App's development it is free to download for Android and iPhone not just for our project parents but to anyone who would find it a useful resource. The App has no connection to any patient data or any hospital system and parents register for it using their own name and private email. Data can only be seen and added by the parents. The App can support multiples as twins or more multiples can be added.

The non-interactive section of the App (educational curriculum, developmental timeline and glossary of terms) can be introduced

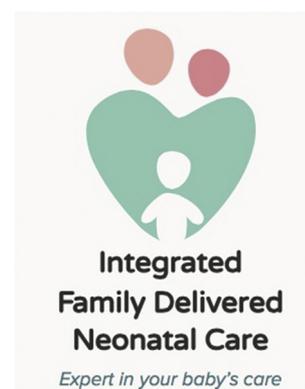


Fig. 2. The logo the IFDC mobile app.

Feeding journey

Knowledge and skill	Familiar with the task, able to explain process		Able to perform with staff's coaching/support		Performs independently under staff's supervision	
	Signed by parent	Signed by staff	Signed by parent	Signed by staff	Signed by parent	Signed by staff
Tube feeding						
I know how to check milk with the nurse, draw up and warm the milk, pour the prescribed volume of milk into the syringe and hold the feed						
I know how to draw milk back up the tube with a syringe, test it on the pH paper and confirm the result with my baby's nurse before feeding						
I know how to support my Baby during tube feeding with skin to skin, positioning and non nutritive sucking and watch for signs of stress and feeding intolerance.						
I have worked with my nurse to develop a feeding plan and am aware of feeding readiness cues.						

Fig. 3. Example from the Competency booklet: tasks around tube feeding.

to women who may be inpatients on antenatal wards holding on to sometimes fragile pregnancy's with the threat of preterm delivery. This group of women are often deprived of appropriate information and resort to searching the internet for support. Sharing the App with them may help to allay some of their fears and empower them with relevant knowledge such as the importance of early expressing and an awareness of the neonatal unit environment.

The developmental timeline takes parents through what to expect in a baby's development and care from 23 weeks gestation to term and gives parents information as to what they can do for their baby week by week.

The curriculum chapters are as listed and go on to form the basis of our parent education programme.

1. Introduction to IFDC
2. Life on the Neonatal Unit
3. Routine Cares
4. Monitoring Vital Signs
5. Working together as a team
6. Medical conditions and interventions
7. Ventilation
8. Fluids and nutrition
9. Making milk for your baby
10. Nutrition and Growth
11. Medication and Drug Chart
12. Developmental care
13. Coping in the NICU
14. The Journey to suck feeding
15. Discharge planning and Post discharge support

For those parents who are not so technically minded, or are unable to download the App all of the materials are available in a paper binder. The neonatal unit is also able to provide parents access to an electronic tablet should they require one to access the App.

The App supports parent education along with the competency assessment booklet, daily care plan, a ward round proforma, and feeding and observation charts (see [Appendices](#)).

1.4. Learning journal and competency assessment booklet

This booklet was designed to go alongside the educational curriculum. It contains an inventory of skills and knowledge that parents can gain whilst on the neonatal unit. It is designed to support their learning needs and reinforce their skill acquisition. It will also help the nursing team to understand where parents are in their journey. Parents will generally go through 3 stages to

achieving competency in a particular subject starting with "being familiar with and able to explain the task" then moving to "being able to perform with support" and finally moving on to "being able to do independently". Each stage requires a parent and nurse signature ([Fig. 3](#)). This can be a particularly useful tool when for example teaching parents pH checking prior to tube feeding from a risk point of view.

1.5. Daily care plan and milestones to home

The daily care plan can be used to let nursing staff know what parents can do for their baby and when they will be coming to the unit that day. It needs to be updated daily. The "milestones to home" is a visual tool parents can use to pinpoint certain stages of their journey and of some of the tasks and skills that need to be achieved before discharge home. Included in these documents is the expressing checklist that takes mother through the first 2 weeks of expressing highlighting "red flag" days that are important in the terms of volume and support given to achieve these volumes. This document also includes our feeding checklist that supports the lactation and feeding journey and support given ([Appendix 1](#)).

1.6. Ward round proforma

Parents spend a lot of time at their baby's cot side and they will know their baby best. They will start to notice the subtle changes in their baby's condition. This can be useful information for the nurses and medical team working in discontinuous shift patterns to think about and discuss on the daily ward round. Parent presence is encouraged on the ward round. The ward round proforma was designed to help parents to summarise information about their baby's journey and current condition. The proforma will help them to give structure to their story and with the way that it is presented. Parents will be supported to use this proforma initially by the IFDC Coordinator and the cot side nurse and they should be encouraged to read chapter 5 of the educational app "Working as a team." As the parents become more experienced the proforma may no longer be needed ([Appendix 2](#)).

1.7. Feeding and observation charts

The observation and feeding chart is where parents can record their measurements of their baby's vital signs, temperature and saturations if they wish. Before being able to use this document parents should be encouraged to read chapter 4 of the educational curriculum "monitoring vital signs" and attend a small group teaching in the subject. On-going support will be given at the cot

side by the nursing team until parents are competent. Their skill acquisition can then be recorded in their learning journal/competency booklet. Parents can also use this chart to record and track their feeding progress although this can be recorded electronically using the timeline function of the feeding diary if they have downloaded the app. As our units are using electronic patient records, it is working well that data charted by parent and validated by a nurse can be entered to the patient's electronic documentation. (Appendix 3).

1.8. Parent education sessions

Before the commencement of our integrated care project parent education was ad hoc. It was usually delivered at the cot-side in relation to involvement in cares or support of expressing and breastfeeding but without structure and pre-planning. Key information such as basic life support was often delivered to families just days before discharge. The IFDC project has given us the opportunity to think about what parents really need to support them through the different stages of their learning journey and start this process a lot earlier.

Having already designed our educational chapters for our App we were able to build our “rolling” programme around this curriculum, enabling us to give that much needed structure. Already having an established multi-disciplinary team (MDT) on our neonatal unit's has meant that we have wealth of knowledge and experience when it comes to teaching about the various aspects of the neonatal journey and whenever possible the MDT are involved in the teaching. Nursing and medical staff are also encouraged to take part in the teaching.

The benefit of having an established integrated family delivered care project is that there is a dedicated coordinator. It takes time and effort to plan and organise the education sessions. Part of the coordinators role is to make up flyers to promote the days teaching and advertise the sessions on the IFDC notice board and the parent's sitting room. They also check in with the individual families on the day to see if there are any changes to their baby's health or condition that may change the topic for that day or the way the session is delivered.

After talking to parents and finding out what they wanted, we decided to start with two education sessions weekly along with a weekly self-care/support group. We quickly worked out that 2 p.m. seemed to be a good time to run the sessions, we didn't want to take parents away from their baby's during ward rounds or keep them from opportunities for skin-to-skin, cares and feeding.

Both neonatal units already have an established weekly parent's support group that is facilitated by a psychologist and a member of the nursing team and is generally used as a safe, confidential space for parents to come and share their experiences of being on a neonatal unit and what it's like to have a premature or sick baby. Parents are invited to “tell their story”; this generates conversations between the families with many shared themes. It's also a time that they can confidentially speak of any challenges or concerns they may be having and how they may be resolved. Practical issues like getting financial support to cover travel cost while on the unit and where you buy food etc. are also discussed. Parents are also invited to have a one to one session with a psychologist if they would find that helpful. We have continued this weekly support group and also offer relaxation classes as part of our parent “self-care” sessions.

In addition to our rolling programme we have a weekly orientation class. All parents are invited to join this class within the first few days of arrival to the neonatal unit. They are shown around and orientated to the hand washing and infection control policies. Depending on the time of year, the visiting policy can be different

for siblings, family and friends. They are informed about the IFDC programme, and encouraged to download the educational App. They get to know how the unit runs and most importantly how they can be involved with their baby's care.

Rolling education programme topics.

- **Expressing and Breastfeeding:** Presented by our lactation consultant, this session covers the importance of early expressing and building a supply for the future. It goes on to discuss the development of sucking and then more practical skills like positioning and attachment at the breast. We use “Small wonders” films ([Best beginnings](#)) to support these sessions. The unit dietician also talks about breast feeding and maternal diet. This session is tailored to meet the individual needs of the family depending where they are in their journey.
- **Positioning:** a member of the physiotherapy team leads on this and discusses how we position baby's to support their breathing and for comfort. This session also goes on to talk about “tummy-time” and goes on to discuss developmental milestones i.e.; sitting, rolling and crawling.
- **Reading your baby:** Presented by the unit occupational therapist, who is an expert in developmental care. In this session we talk about baby cues and what a baby maybe telling us i.e. how the parent may recognise when their baby maybe feeling any pain or discomfort. The Bliss publication “Look at me I'm talking to you” ([BLISS](#)) supports this topic as well as the book “Caring for your baby on the neonatal unit-a parents handbook”- By Inga Warren and Cherry Bond ([Inga Warren and Cherry Bond](#)).
- **Parental voice:** Our speech and language therapists deliver this session, designed to teach parents the importance of them talking and singing to their babies and how this impacts on their baby's development.
- **Parent craft:** Parents are supported to learn how to give mouth care with their milk, do supportive side lying nappy changes; wrapped baths; give medicines for discharge. Again these sessions are tailored to meet the needs of the family and are usually delivered at the cot-side.
- **Discharge planning:** this session covers safe sleep and basic life support along with practical advice around car seats and slings.
- **Pharmacy session:** Parents are invited to come with their questions about any medicines their child may be having currently and can ask about anything from vitamins to immunisation. This session is presented by the ward pharmacist.
- **Aspects of prematurity:** This is class is facilitated by a neonatal consultant. The parents depending on their needs for that day set the theme.

Education sessions are quite informal; wherever possible they are in the parent's sitting room over a cup of tea and a sandwich, meaning families also remember to eat lunch. It's important that parents are able to learn in an environment that supports their individual needs, where they feel safe enough to share their feelings and ask questions. Each session is around 45 min long and is guided by a lesson plan ([Fig. 4](#)). They usually take the form of a short presentation or video followed by practical demonstrations with dolls and various props. Other sessions are facilitated with a question and answer format with the parents deciding the theme. The education programme has been designed to give the families the skills they need to become confident carers for their baby's and enable them to complete the competencies in their learning journal that supports their learning. Any parents with a child on neonatal unit are welcome to join the education sessions, not only the ones participating in the IFDC project.

We need to understand where a parent may be in their individual journey. We use a “traffic light” system throughout our App

Title of lesson: Establishing Breast/Bottle Feeding				
Relates to Chapter 14 : The Journey To Suck Feeding				
Aims for this session: We want parents to know and achieve:				
<ul style="list-style-type: none"> • An understanding of how a baby develops suck feeding skills • How to read Baby's feeding cues • How to position Baby at the breast • How to work out how Baby is feeding and wean from tube feeding • How to support the bottle fed baby • Feeling prepared to take Baby home • To learn about responsive feeding 				
Pre session learning: Read chapter 14 of the educational curriculum				
Materials:				
<ul style="list-style-type: none"> • iPad with curriculum chapters/Paper binder curriculum chapters • laminated bite size presentation • Small wonders film 7 "feeding independently" • Leaflets: Top-up chart; Breast feeding your baby at home; Supporting the immature baby with bottle feeding; Responsive bottle feeding • Dolls; knitted breasts; Feeding Cushions; Nipple shields; Bottles & teats 				
Lesson Plan (around 50 mins)	Time	Objectives	Activity	Resources
	5mins	To understand how sucking skills develop.	Mini lecture	Flip chart
	10mins	How to read feeding cues.	Watch dvd clip	Small wonders/iPad
	10mins	Positioning and attachment for breast feeding	Practical demonstration	Dolls/ knitted breasts/ feeding cushions
	7mins	Transitioning from tube to breast/bottle	Watch dvd clip Mini lecture	Small wonders/iPad leaflets
	10mins	Ready for home?	Q&A	Leaflets
	7mins	Responsive feeding	Q&A	leaflets
Measuring success		Follow up post session/ achieving competencies		
Reflection		Parent evaluation/feedback		

Fig. 4. Example of lesson plan.

and staff teaching to help us to understand and gauge how the parents might be feeling.

Initially parents report feeling overwhelmed and powerless when they first arrive in this new environment so it's important not to overburden them with too much information at this stage but good communication at the cot-side is vital.

The middle stage they may start to feel more involved and informed and able to process things a little better and ready to attend some group education sessions. In the final stage they are starting to feel more confident and see themselves as the primary caregiver for their child and equal members of the team.

1.9. Evaluation of the education programme

Parent feedback helps measure the success of the IFDC education programme and make sure we are getting it right. At the end of each session parents are invited to evaluate the lesson they have attended and rate its content and how relevant it was to them on a scale of 1–5 with 5 being the highest. There is also the opportunity for them to give free text feedback and give any comments and suggestions they may have. They are also asked to recommend topics they would find beneficial for the future.

"Very informative session which chips away at parents fears and empowers us with knowledge ..."

"It's really great to be able to ask questions and just chat to the ward pharmacist about all sorts of aspects of my daughters drug chart and medicines she may have in the future"

"My children sat in on the physio class and were then able to update both me and my husband. This really made them feel part of their brother's journey-maybe a Dads class would be good too"

"The fortnightly Q&A with the Consultant is a great session to attend. We get to discuss many aspects of prematurity"

"Very informative session, good content, well delivered. Plenty of time for Q&A's throughout and at the end"

"Really useful relaxation session, I really lived the visualisation and will definitely use in the future"

We are just at the beginning of our IFDC journey and keen to learn from our own reflections to improve our program. The education sessions have worked best with a group of parents who are at similar stages in their journey as it enables the lesson to suit the

all family's needs and the benefits of delivering it in a group setting, which allows for shared ideas and generates conversation and discussion between parents. In the Canadian study parents were recruited in groups of four, enabling them to progress through their journey at the same pace with similar learning needs at each stage.

We hope in the future to be able to broaden our education programme; suggestions made have been for a “Fathers Group”, weekend or evening teaching sessions and for siblings and grand-parents to be able to attend education sessions in particular basic life support. Over the next few years we hope to include our ever growing “army” of veteran parents in our education sessions.

2. Summary

Parent education is an important “pillar” of our Integrated Family Delivered Care (IFDC) programme. If parents are to be enabled to be “experts” and feel like they really are true partners in their baby's care they will need to receive consistent information as well as a supportive education programme that has been tailored to

meet their needs. It is vital that we take into consideration how the parents of a sick child may process information and how this may change as they progress through the neonatal unit. It is essential that a comprehensive parent education programme is designed in any similar FIC care bundle.

Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.jnn.2017.11.008>.

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