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Integrated family delivered care project: Parent education programme

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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.

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 multidisciplinary 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

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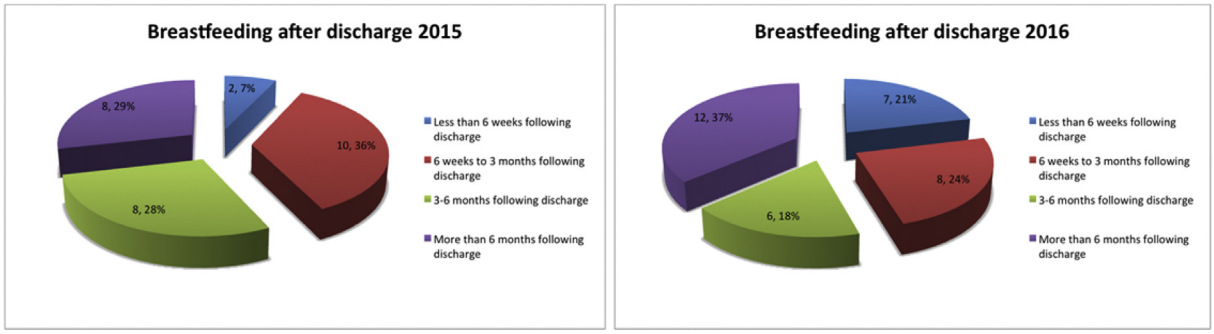

Fig. 1. Breastfeeding after discharge based on the 2015 and 2016 parental survey.

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.

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