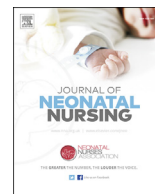




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## Innovations: Supporting family integrated care

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## ABSTRACT

Family integrated care is delivered in a supportive environment where parents are supported with education and competency based training and the neonatal unit policies and guidelines are conducive to providing such care and nurturing such approach. Use of digital technology has revolutionised and shaped the modern world. Use of mobile-based application can help parents to develop their knowledge and confidence; cameras and videos can help parents to stay in touch with the vulnerable infants even when they are not next to their loved ones. In this article we glance through the innovative ways of breaking through the barrier of staff and parent education, communication and access of the parents to the cotside using innovative ideas and digital technologies.

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## 1. Introduction

Family integrated care (FIC) is built on the basic principles of mutual respect and dignity, competency based training, education and active involvement of the parents in delivering care for their vulnerable infant admitted to the neonatal unit (Jiang et al., 2014; O'Brien et al., 2013). However, the environment, infrastructure, layouts and governance around neonatal care may not make it conducive for developing and nurturing such an approach. We are aware that in certain well-developed countries new neonatal units are built with the idea in mind of having the families living on the unit together with their babies; but such facilities and options may not yet be realistic in many neonatal units including the UK.

Therefore, active involvement of the families and a collaborative environment between the healthcare professionals and the parents often fall short, even with the best of intentions (Redshaw et al., 2010). Innovative ideas and use of technology can help to overcome some of these shortfalls. Parent education, access of the parents to the cotside and communication with the parents can minimise stress and anxiety, help them to gain control back and improve their coping skills. Healthcare professionals may find it difficult to embrace this paradigm shift in the FIC model from a doer to a facilitator and consultant for the parents (Kjellsdotter et al., 2017). Healthcare professionals, especially nurses are also constantly stretched in the face of severe shortage of skilled staff in neonatal units. Even providing education and updates for the

nurses in groups is very challenging. In such a situation, innovative ideas to train nurses are important to make them well conversant with this new model of care.

The FIC model developed by the Mount Sinai Hospital team is based on a large amount of experience co-designed material which is accessible in <http://familyintegratedcare.com/>, the majority of these materials are paper based. In this article, we will explore some of the new approaches which are taking family integrated care to the next level, by educating parents about neonatal care and practices, by training staff in innovative ways and by creating a friendly and welcoming neonatal environment for the parents.

## 1.1. Integrated family delivered care mobile app

Imperial neonatal service in collaboration with veteran parents and the core working group on family integrated care have developed Integrated Family Delivered Care (IFDC) mobile app to support parents in this new care model (Banerjee et al., 2017). In the modern world with easy access to internet parents often resort to online information from various search engines and forums where discussions around certain topics of medicine are generally regarded as more pessimistic and on majority of occasions unreliable; this can result in significant distress and anxiety (Usui et al., 2011). Both the POPPY project and Picker National Surveys highlighted the problem of inconsistent information received by parents from different members of the neonatal team (Redshaw et al., 2010). Providing clear consistent information is the key to parental education and understanding. The IFDC mobile app is freely available for both mobiles and tablets from both Apple Appstore for iOS

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devices and Google Playstore for Android devices for any parents around the world who are in need of information around neonatal care of their sick preterm infant. The App was funded by the Imperial Health Charity.

This app was experience co-designed with veteran parent focus group, medical, nursing and allied health professionals. There were several parent focus group discussions around the app design and content, which were attended by numerous parents and many healthcare professionals to finalise the end product. The app design was created by Pocket Explorers Limited (Hannah Catmur) and the app was developed by Propellers app developing company (Mike Adams). The Quality Improvement and Information Governance team from Imperial College Healthcare NHS Trust (ICHNT) were actively involved to make this app compliant with trust information governance, making sure the quality of the app was not diminished.

Parents can download the app and register with the required information with their username and password at the very beginning of their journey soon after admission. The personal details and diary entries in the app are only accessible to parents as it is password protected; the app can sync between various iOS devices making it easy to access from home, hospital or workplace. The IFDC mobile app can handle multiples upto quadruplets, which mean that parents with multiples, as is the case for many preterm births, create one entry with their username and password and will be able to add all their infants as multiples within the same entry separately. This is not the case for many other neonatal mobile apps. The IFDC mobile app has got an interactive and a non-interactive section. The non-interactive section is divided into several sections. The main focus of the non-interactive section is to deliver parental education and consists of fifteen chapters around

various aspects of neonatal care from admission to discharge written by our multidisciplinary team in collaboration with our veteran parent focus group (Fig. 1). To our knowledge, this is the only online parent friendly consistent resource in the world available to parents of sick preterm infants to such as high level. The chapters are comprehensive, written by trained professionals and co-designed with veteran parents. The chapters contain details around general aspect of the neonatal unit and the team, monitoring appliances, ventilators, medical conditions such as chronic lung disease and oxygen dependency, as well as developmental care, lactation and breast-feeding in premature infants. There are details around oral medications and preparation for discharge home. There is a glossary of common terms in the non-interactive section which is co-designed by the parents, explaining some of the medical jargon and abbreviations commonly used by the healthcare professionals in discussion with the parents (Fig. 2). The app also links to other reliable and trusted resources available on the internet. For example the Best Beginnings Small Wonders films that we used to give as a DVD copy but found many parents did not access it. In this way they can watch films easily via the links in the app.

Another important feature of the non-interactive section is the developmental timeline that we created, which is again a very unique feature. The developmental timeline is an educational tool around the development of the premature infant around various gestational ages from 23 to 42 weeks. This tool informs the parents about their general development, brain and sensory development, motor development and behaviour and about the neonatal care they generally receive around those gestations on a weekly basis, tailored to neonatal care (Fig. 3). It also informs parents about what they can do at those gestational ages regarding touch, bonding,

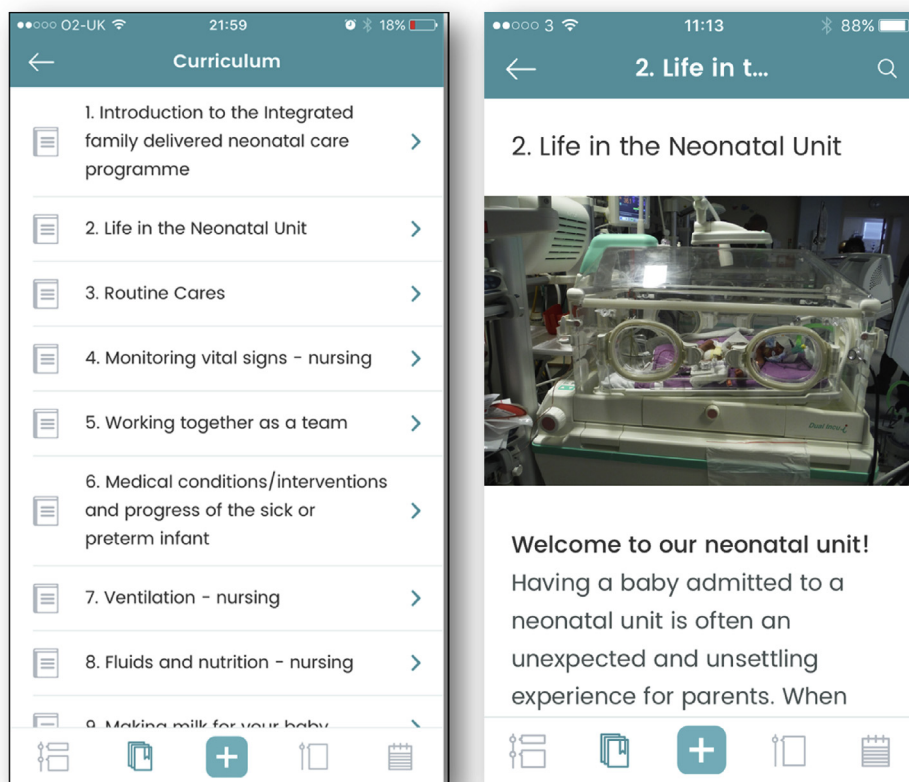


Fig. 1. Parent education training curriculum in the IFDC mobile application.

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