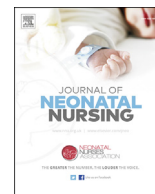




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Development of outcome measurement tools for the integrated family delivered care project

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ABSTRACT

The Integrated Family Delivered Care Project (IFDC) aims to empower parents to become experts in their baby's care, and create an ethos, which truly reflects and responds to the families' unique needs. This quality improvement project was developed based on emerging evidence from research studies, which has demonstrated the effectiveness of Family Integrated Care (FIC) model. Although this programme was designed as a quality improvement (QI) project using QI tools to avoid the inflexibility and certain barriers that academic research and randomised studies are associated with it is imperative that we collect reliable data on the effect of this new care model. As part of the IFDC project, a set of pre-defined outcome measures will be collected for infants enrolled in the IFDC project; these measures will be compared with retrospective matched controls cared in traditional neonatal care settings.

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1. Introduction

The aim of the Integrated Family Delivered Neonatal Care (IFDC) project at Imperial College Healthcare NHS Trust was to improve parent-experience, parent-infant bonding, parental mental health, and infant health outcomes by pioneering a new care model at Imperial College Healthcare NHS Trust (ICHNT) based on international evidence. The Plan-Do-Study-Act (PDSA) cycle (Fig. 1) (Langley et al., 1996) was created to demonstrate the model for improvement for this quality improvement (QI) project. The PDSA (Langley et al., 1996) cycle is an experimental learning approach, which allows for continuous reflection, evaluation and change at all stages of the project.

There is growing evidence that educating and engaging parents with the care of their baby can reduce their anxiety, improve parent experience and facilitate bonding. Current evidence (Levin, 1994; O'Brien et al., 2013; Bracht et al., 2013; Macdonell et al., 2013; Pineda et al., 2014; O'Brien et al., 2015) has established now not only the feasibility of Family Integrated Care (FIC) in neonatal settings but actually proved that clinical outcomes are better than traditional neonatal healthcare models. To decide what dataset to collect in our QI programme, outcome data used in different FIC studies were reviewed. The evidence for FIC dates back to 1979,

when a shortage of trained neonatal intensive care nurses in Estonia prompted Levin to implement a "Humane Neonatal Care" model (Levin, 1994). This unexpectedly resulted in significant improvement in weight gain, a reduction in infections, length of stay in NICU, a reduction in nurse utilisation and overall improved satisfaction among parents and staff (Levin, 1994).

Professor Shoo Lee from Canada closely investigated the Estonian model and felt that this type of care is feasible and could be similarly effective in more developed countries. The pilot cohort analytical study carried out in 2011–2012 at Mount Sinai Hospital, in Canada, confirmed the feasibility of FIC in a multicultural western country (O'Brien et al., 2013). Infants born ≤ 35 weeks gestation with a parent willing and able to spend ≥ 8 h a day was included in the study ($n = 42$ families). For each infant, two matched controls were identified from the previous years' database. The primary outcome of the study was weight gain (over 21 days following enrollment). Secondary outcomes included other medical outcomes as breastfeeding at discharge, number of clinical incidents, mortality and major morbidities related to prematurity as nosocomial infection, intracranial haemorrhage, necrotizing enterocolitis, retinopathy and bronchopulmonary dysplasia. Parental Stressor Scale (PSS) was used to measure parental anxiety in the first week following admission and before discharge. Parental experience was assessed by using semi-structured one-to-one interviews prior to discharge. O'Brien and colleagues showed that in this care model weight gain improved; and there were some tentative improvements in secondary outcomes (O'Brien et al., 2013).

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Fig. 1. PDSA cycle.

From the parents' responses, several themes were identified around FIC including gaining knowledge and confidence; better relationships with the medical team and other parents (O'Brien et al., 2013); and a reduction in the measurable degree of stress in parents (O'Brien et al., 2013; Bracht et al., 2013). This pilot study has several limitations. It was highlighted that as sample size was small, and statistical power was limited; therefore a larger randomised controlled trial was required to further evaluate the efficacy of FIC. Additionally as not all eligible parents were approached due to limited cot capacity; it was not possible to

conclude that the results are generalisable to the entire patient population in the NICU.

Therefore a further clustered randomised controlled trial was undertaken in 16 NICU's across Canada and Australia to evaluate the efficacy of the FIC model. The primary outcome of the study again was weight gain (over 21 days following enrolment), and secondary outcomes included breastfeeding rates, clinical outcomes, safety, parental stress and anxiety. This study finished enrolment in September 2015, and results are due to be published soon. These results support the concept that medical outcomes and

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