



# Life is a rollercoaster...What helps parents cope with the Neonatal Intensive Care Unit (NICU)?



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Available online 12 May 2015

## KEYWORDS

NICU;  
Family centred care;  
Pre-term;  
Parent coping;  
Neonatal

**Abstract** The birth of a pre-term baby is an acutely stressful event for parents. Consideration of the factors which help parents cope with NICU can help achieve the best possible outcome for NICU babies. The study objective was therefore to understand better the factors which support coping. A consecutive sample of NICU parents participated in semi-structured interviews which focussed on their experience. The setting was a UK Level 2 NICU and participants were nine parents representing seven families. Thematic analysis was used to analyse the data. The main theme extracted from the data described the Emotional Rollercoaster of NICU. Additional themes identified factors which helped or hindered coping: Baby Well-being, Physical Environment and Other People. In conclusion, none of the factors alone explain positive coping, however the findings give useful information about optimal NICU conditions to parental promote psycho-social wellbeing.

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## Introduction

Increasing fertility rates and advances in reproductive medicine mean that more pregnancies in

the UK are viable than ever before. One impact of these advances is that the number of babies requiring specialist NICU care is rising year on year. For example, there was an 8–10% increase in survival rates in babies born at less than 26 weeks gestation (Department of Health, 2009). This means that the lives of an ever growing number of babies and families are being shaped by their experience of the NICU environment.

The highly technical and medically focussed NICU is vital in giving babies the best possible chance in life. In this environment there is a risk that little attention is paid to the psychological needs of both babies and families. It is easy, however, to make a case for considering psychological needs. Research shows that mothers with existing mental health problems are at higher risk of premature delivery or having a lower birth weight baby (Department of Health, 2009), that mothers of pre-term infants are at increased risk of relationship problems, family stress & financial problems than their counterparts with full term babies (e.g. Carter et al., 2007) and that a preterm birth impacts negatively on the attachment relationship between mother and baby and on maternal responsiveness to the infant (Evans et al., 2012).

A number of researchers have outlined specific ways in which time spent in NICU is stressful. Carter et al. (2007) suggest that four specific aspects of the NICU experience can exacerbate stress for parents: the physical environment, the baby's physical appearance or behaviour, staff–parent interactions and alterations in the parental role. Giving care to a newborn infant is a fundamental maternal attachment behaviour, and one which is disrupted within the NICU environment (as described by Obeidat et al., 2009). The experience of the NICU parent is often that of being one of many people caring for their child. This exists in sharp contrast to the expectation held by many parents antenatally and such a dichotomy between the anticipated outcome of pregnancy and the actuality of parents' experience must be considered an important factor in predicting coping.

This friction between reality and expectation is recognised by the 2009 Toolkit for High Quality Neonatal Services, in which the Department of Health (DoH) identified 'Care of the baby and family experience' as one of the eight key principles for quality neonatal services. The Toolkit promotes "a family centred philosophy of care that helps families whose baby is in hospital to cope with the stress, anxiety and altered parenting roles that accompany their baby's condition." (Department of Health, 2009) and goes on to

suggest that the physical, psychological and social needs of babies and families are held at the heart of all care given, with the aim of enhancing attachment and improving long term outcomes.

To this end, the present research was conceptualised as a way to understand better the experience of families and to consider factors which support coping in NICU. In order to do this a semi structured interview was conducted with a sample of NICU parents.

## Method

### Service context

The Dyson Centre for Neonatal Care at the Royal United Hospital in Bath was built during 2010–11, following investment through the 'NICU Space to Grow Campaign'; a partnership project between the public and charitable sectors. This paper describes the use of semi structured interviews to explore parent perceptions of the overall NICU experience.

### Participants

Participants were mothers and fathers of pre-term babies born at 26 weeks or later. All families who met the study criteria during the time frame were approached and asked to participate in the project (approximately 30 families were initially approached). Seven families consented to be interviewed; either prior to their baby's discharge from the unit and/or 6 weeks after discharge. Three families had twin births and four families had singleton babies. All had been on the NICU for at least four weeks before the discharge interview took place.

### Procedure

Face to face semi structured interviews were conducted with eight parents (five mothers and three fathers), representing six families and a short telephone conversation took place with one additional mother from the seventh family. All pre-discharge interviews took place in the NICU and the 6 week follow up interviews took place at the family's homes. All interviews were audio taped and field notes were taken during the telephone conversation.

The interviews began with each parent being asked to give an account of how their infant(s) came to be in NICU. Parents were encouraged to speak freely about their experience and to focus

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