



Mothers' perceptions of family centred care in neonatal intensive care units

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ABSTRACT

Objective: To explore mothers' perceptions of family centred care (FCC) in neonatal intensive care units (NICUs) in England.

Design: The qualitative experiences of 12 mothers from three NICUs in the UK were elicited using individual interviews. A thematic network analysis was conducted on the transcribed interviews.

Main outcome measures: A central global theme supported by a number of organizing themes were developed reflecting the views of the mothers and their experiences of FCC.

Results: A global theme of "Finding My Place" was identified, supported by six organizing themes: Mothering in Limbo; Defence to the Expert; Anxious Surveillance; Muted Relations; Power Struggles and Consistently Inconsistent. Mothers experienced a state of liminality and were acutely sensitive to power struggles, unhelpful relationships and inconsistencies in care. To try to maintain their equilibrium and protect their baby they formed differential relationships with health professionals and remained in a state of anxious surveillance.

Conclusions: This study illustrates that despite the rhetoric around the practice of FCC in NICUs, there was little in the mother's narratives to support this. It is of the utmost importance to minimize the consequences of the liminal experience, to improve staff–mother interactions and to facilitate mothers' opportunities to be primary caregivers.

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Introduction

The term "family centred care" (FCC) has been used to describe a model of health care which recognizes the significant role played by family members in the well-being of a hospitalized child or infant [1]. Although there is no simple definition for FCC, the Institute of Patient- and Family-Centered Care [2] describes it as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families". This rather broad definition reflects the multi-faceted nature of FCC and its application in different contexts and different cultures. Within neonatology, FCC has evolved into an extensive spectrum of services and activities incorporating a range of environmental, educational, psycho-social and behavioural characteristics all of which seek to place the family at the heart of care planning [2–5]. In the last two decades, FCC based interventions have been developed to support the parent–child attachment relationship [6–9]. There is convincing evidence about the

positive effects of Kangaroo Mother Care [10–11], but studies suggest there are huge differences in the provision of facilities to enable skin-to-skin care and parental involvement [12,13]. A recent European survey, for example, found that 100% of included units in Sweden had reclining chairs near babies' cots and 100% had beds for the parents whilst in the UK these figures were 11% and 77% respectively [14].

The comprehensive nature of FCC is perhaps best illustrated by Harrison's "Principles for Family Centered Neonatal Care" [15]. This document, drawn up by a committee including neonatologists, neonatal nurses and the parents of premature infants, highlights 10 key strategies most of which revolve around the formation of authentic, collaborative parent–health professional relationships in a supportive, family-friendly environment (Table 1).

Collaboration between nurses and parents is essential for implementing FCC in NICUs [16]. A positive and trusting staff–mother relationship enables mothers to connect to their infants whereas a negative relationship may lead to disconnection [17,18]. Furthermore, when mothers feel emotionally supported and have trust in the relationships with nurses, the transition from traumatized onlookers to competent, confident parents is greatly enhanced [19,20]. Reik, Rempie, Scott, Brady-Pryer and Van Aende [21] suggest that

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