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Life is a rollercoaster...

What helps parents cope with the Neonatal Intensive Care Unit (NICU)?

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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 Wellbeing, 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.

Keywords: *NICU, family centred care, pre-term, parent coping, neonatal*

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 taking 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 on aspects which felt important to them. The interviewer probed for more detail when issues around coping were raised. In each interview parents were asked three questions:

- i) How wound up & anxious have you been over the last week? (On a scale of 1 – 10)
- ii) Can you describe what it has been like for you to be on the unit over the last week?
- iii) Have any aspects of the NICU environment been difficult to deal with?

At the follow up interviews parents were asked to revisit the questions from the initial interview and reflect on their experience now that some time had passed.

The researcher's perspective

The first author of this paper is a mother. She had no prior experience of NICU, having had a healthy, full term baby herself.

Analysis

All interviews were transcribed verbatim and then checked against the tape recordings for accuracy. Transcripts were interrogated using thematic analysis conducted from a realist position, assuming that parents' accounts were accurate representations of their experience. An inductive approach was taken to the initial analysis, enabling themes to be developed from the data without influence of previous research findings.

Thematic analysis was then conducted following the six phases laid out by Braun & Clarke (2006). Once initial themes had been identified all transcripts were re-read to ascertain whether the collected themes appeared to fit with the data. Themes were further refined at this point. The themes were then reviewed by two other researchers and assessed for goodness of fit with the data. Suggestions were made for further refinement of some themes, however overall agreement between researchers was good.

RESULTS

Four key themes were extracted from the interview data, mostly comprised of positive elements but with some examples of factors which hinder coping. The four themes are 1) 'Rollercoaster of Emotions'; 2) 'Baby Wellbeing'; 3) 'Physical Environment'; and 4) 'Other People'. Other People is sub divided into 'In The Same Boat', 'A Matter of Choice', 'Talking Helps', 'Feeling Involved' and 'Flexibility'. Each theme is discussed in more detail below, however due to restrictions of word length only very brief descriptions are given.

1. Rollercoaster of emotions

Interwoven with themes around coping was talk about the emotional rollercoaster of the NICU experience. Parents talked about feelings of guilt, anxiety, fatigue, joy and apprehension characterising their experience. They perceived these as interacting with the emotional experience of other parents which is naturally shared when families spend so much time together. All parents interviewed described this theme. These descriptions encapsulate the essence and unpredictability of the NICU experience and set the stage for exploration of other themes.

“One of the first things I remember being told about a NICU unit...was that this is a rollercoaster...you have your highs, you have your lows...it is completely a whirlwind...”

(NFF mother p.2)

The physical environment

The building of the new unit seems to have created space for mothers and fathers to focus on parenting and the quality of their experience. All parents spoke in positive terms about the environment when asked directly and all but one suggested they were less stressed than they would have been in a different environment. Two mothers suggested that the environment had helped them to bond with their babies, although others did not make this association. All parents were aware that the unit was new and several commented that they thought being in the old NICU would have made their experience more stressful. The environment is therefore viewed as an important positive foundation upon which other aspects of the experience can sit.

“I think the environment is...it’s on a stress level, if you’re in a poor environment, you’re going to be in a poor mood, you know, and you’re going to either be wanting to get out of there quicker or, if it’s in a nicer environment like this, you’re not going to...you’re going to relax about things...”

(NFH father p. 13)

Baby wellbeing

The impact of baby wellbeing on coping stood out and every parent spoke to this as being important in predicting their own emotional wellbeing. Although, as one parent highlighted, no NICU baby is a ‘well’ baby, the more progress the parents perceived their infants to be making, the better they felt emotionally. Although in this qualitative study it is not possible to make statements about moderating or mediating relationships between factors, it is probable that baby wellbeing moderates parental stress and anxiety throughout the NICU journey. This recurred as a robust theme and was the aspect that

parents most often referred to when estimating their Subjective Units of Distress (SUDs) over the last week.

“...this operation he had not long ago...yeah that was a bad time...once we knew it was done and it was being dealt with...you start to relax again.”

(NFF mother p. 6)

Other People

The presence of strangers is one of the key differences between NICU & a home environment. This theme and its sub-themes reinforce the point that relationships with other people within the NICU environment are a key determinant of parental coping. Parents described the difficulties inherent in group situations; that one will get on well with some people, not well with others and everyone will live according to slightly different rules.

i) In the same boat

When talking about other parents most participants spoke positively and reported relationships which helped to normalise their own experience and promoted coping.

“It makes you realise...you’re not on your own, everybody else is dealing with it as well....Sometimes you just give each other a bit of strength when you need it...and someone will say something nice...and it makes you go ‘oh yeah, actually I am doing ok...I am getting there.”

(NFF mother p.15)

ii) A matter of choice

Several parents, however, also alluded to the fact that other parents and staff could add to the stress of the experience and that not having choice was related to increased stress.

“You have to deal with people you wouldn’t normally socialise with...like Big Brother...you can’t just think ‘oh, I won’t come back’ because you want to see your baby...that was the hardest, having to bite your tongue.”

(NFC mother p. 2)

iii) Talking helps...but not too much

Some parents also talked about the value of normal conversations with staff that helped them to get through the days and retain a sense of connection to the world outside NICU.

“...sometimes its chatting to the nurses as well...they’re fantastic...you can have a normal conversation and...it doesn’t have to be about your baby...it can be a chit chat about anything...”

(NFF mother p.15)

While conversations with staff and other parents were primarily positively perceived, most parents talked in negative terms about visitors to the unit. These additional people and their conversations contributed to a sense of noise and busy-ness which, without exception, parents experienced as stressful. There was resentment that other parents did

not appear to show consideration when hosting more visitors than were allowed and otherwise flouting the rules.

“But a lot of the time there’s just people there...for hours on end...who may be just providing lifts and...you feel you’ve got nowhere to just escape from...to just have a little bit of quiet down time.”

(NFG father p. 5)

iv) Feeling involved

Several parents talked about feeling included in their baby’s care and how valuable this was to them. All but one of the mothers interviewed said that they had wanted information at times but been reluctant to ask questions or say something to staff because they worried about being a bother, seeming over-anxious or interfering. Factors which seemed to help with this included familiarity with the staff member and their physical availability.

“[I will] often ring up and ask how they are and...nothing [is] ever too much trouble...and they always use the babies’ names as well, and it all just helps...”

(NFG mother p.4)

Parents also shared examples of times when they felt excluded or not given information and these created more stress for them. This led to some feeling confused about what to do for the best for their baby.

“...if one nurse...hasn't told you when you get your baby out for a cuddle to make sure you keep it under a blanket...then the next nurse comes on...and then you feel a bit bad because they've suddenly said to you 'well why haven't you got a blanket on him?' and it's like 'well no-one told me!'”

(NFF mother p.14)

v) *Flexibility*

Most parents spoke positively about how nursing staff seemed to consider parental needs and try to meet these wherever they could.

“...as soon as they can let you do anything with the baby they do, even if you can imagine it probably makes their life more difficult and their job more time consuming, as soon as they possibly can let you take as much ownership as possible, they do and...and that makes such a difference.”

(NFG mother p. 3)

DISCUSSION

The themes developed from the interview data suggest that the optimal conditions for coping appear to be having a relatively well baby, in a calm environment, shared with parents who hold similar values to your own, staffed by flexible, friendly professionals who seek to promote parental involvement in care at every possible opportunity. If each of these elements is in place then parents feel better equipped to deal with the emotional rollercoaster of NICU. If any of these is missing or worse, replaced by its opposite (e.g. other parents with whom you have nothing in common, nurses who are inflexible and exclusive of parents), then parents find it harder to cope with the experience.

This is the first study to place significant emphasis on relationships with other parents and, as such, opens the door to further research in this area. Some initial support for parent-parent support groups has been shown by older studies (e.g. Dammers and Harpin, 1982), however methodological problems with such studies and the absence of more recent research encourages caution in this area.

With the exception of the above, the current findings do not deviate significantly from previous research in this area. In the most recent comprehensive review on the topic of parenting in the NICU, Cleveland (2008) identified a number of parental needs in relation to NICU and four categories of staff behaviour which helped these needs to be met. The present findings map closely onto the staff behaviours identified (emotional support, parent empowerment, a welcoming environment and parent education), reinforcing the importance of these aspects of care. A number of previous studies have identified the importance of promoting parental involvement in care (e.g. van der Pal et

al., 2013) and Family Centred Care interventions such as Creating Opportunities for Parent Empowerment (COPE - Melnyk et al., 2006) have been developed to meet this need.

These data were gathered from a small sample of parents recruited from a single site and it is difficult to know how representative their views may be of the wider population of NICU parents. Some parents may also have chosen not to be interviewed because of strong negative views about the unit and this may mean that the sample was biased towards those with positive experiences. Given that all babies were still resident in NICU at the time of the interviews it may have been difficult for parents to be critical of any aspect of their experience and so again the interviews may have elicited comments with a positive bias.

This study represents an important step forward in our understanding of the experience of NICU parents, despite the limitations outlined above. Previous research has largely been conducted by nurses and other NICU professionals in non-UK NICUs. This is one of the few studies to be carried out in the UK and the first to be conducted by a psychologist in clinical training. The fact that the researcher was not a member of NICU staff may have helped parents to present a more honest perspective than they would have to a member of NICU staff involved in the care of their baby.

NICU nurses are in the unique position of being asked to carry out a traditional nursing role while also implicitly helping parents to manage the emotional and practical consequences of having a baby in NICU. This appears to be both a privilege and a burden, termed by one team of researchers as 'walking the line between the possible and the ideal' (Hall et al., 2010 p. 2). It is important that discussion of this relationship is

able to take place without it being perceived as placing an additional pressure on staff. While this research did not place paramount importance on the nurse-parent relationship, particular characteristics of the relationship were key to coping. Other authors (e.g. Reis et al., 2010) have described this relationship in more detail and have identified key nursing behaviours of perceptive engagement, cautious guidance and subtle presence as characterising the ideal position.

Further exploration of peer relationships within NICU is also warranted. Evaluation of 'buddy' systems and parent support groups will further understanding of the contribution such interventions offer in reducing parental stress.

CONCLUSIONS

These findings suggest that relationships – both with staff and other parents - are key factors which determine parental coping. Parents reported that majority of NICU staff already demonstrate empathic, supportive care, however this is not resource-free and health care staff need to feel well supported themselves in order to be able to support and care for others adequately.

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