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University
of Glasgow

**An exploration of parents' experiences of having an infant who requires
surgery using Interpretative Phenomenological Analysis
and Clinical Research Portfolio**

Volume I

(Volume II bound separately)

Ruth A. Hind

MA (Hons) MSc

*Submitted in partial fulfilment of the requirements for the degree of Doctorate
in Clinical Psychology*

Institute of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow

October 2014



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CHAPTER 1: SYSTEMATIC REVIEW

A systematic review of how parents experience the transition of their infant from the Neonatal Intensive Care Unit to home?

Ruth A. Hind

University of Glasgow
Mental Health & Wellbeing
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Prepared in accordance with guidelines for submission to the Journal of Reproductive and
Infant Psychology (Appendix 1)

Abstract

Background: The birth of an infant requiring admission to a neonatal intensive care unit (NICU) is emotionally challenging for parents. As neonatal intensive care improves, more infants are being discharged home to their parents. Parents' experiences of their infants discharge and the support they receive can impact how parents cope, the parent-infant relationship and their infant's development.

Objectives: This review aimed to systematically examine and synthesise qualitative studies of parents' experiences of their infant's discharge home.

Method: Systematic searches of Medline, CINAHL, Psychinfo, Embase and Web of Science were conducted. Reference lists, selected journals and Google Scholar were hand searched. Six articles were identified for inclusion and their quality assessed. Meta-ethnography was used to synthesise the studies.

Results: All included articles were deemed to be of acceptable or good quality. Six themes were identified: mixed emotional response; overwhelming sense of responsibility; commitment; hope for the future; developing the parental role and changed perspective.

Conclusions: The review highlighted the need for professionals to consider the emotional impact of NICU discharge and the associated responsibility that parents feel for caring for their infant. Suggestions for supporting parents during the pre- and post-discharge stages are made.

Key words: Qualitative systematic review, parents' experience, NICU discharge

Introduction

The birth of an infant is a time associated with significant change for parents of healthy infants, including adjustment to parenthood and the responsibilities associated with caring for a new baby (McKim et al., 1995). For parents whose infant is born prematurely (before 37 weeks gestation) or unwell and requiring admission to the Neonatal Intensive Care Unit (NICU), the experience of becoming a parent has added complexities. Approximately 11% of all live births in Scotland each year are admitted for neonatal care (Scottish Government, 2009), the majority of whom are preterm infants. As medical care improves, the survival of infants born prematurely or ill increases and consequently more infants are discharged home to their parents (Moore et al., 2012).

A large number of studies have investigated the experience of parents who have an infant that requires admission to a NICU. A qualitative systematic review (n=14) found parents of NICU infants experience depression, anxiety, stress and loss of control, and can oscillate between feeling included or excluded from their infant's care (Obeidat, Bond & Callister, 2009). Involvement in care is important as it can facilitate the development of parent skills and the parent-infant relationship (Fegran, Helseth & Fagermoen, 2008; Wigert, Johansson, Berg & Hellström, 2006), which are likely to impact on how parents experience their infant's discharge home. Cleveland's (2008) systematic review investigated parental needs whilst their infant is in NICU and the staff and service factors that can meet these needs. This review included 60 studies, integrating quantitative (n=30), qualitative (n=28) and mixed methodology (n=2). Cleveland (2008) identified six primary needs of parents: accurate information and inclusion in infant care; parent vigilance and protection of the infant; need for contact with the infant; to be positively perceived by staff; individualised care and a therapeutic relationship with staff. Fewer studies have been conducted that investigate parents' experiences of their infants discharge home from NICU (e.g. Griffin & Pickler, 2011; Rowe & Jones, 2010) and infant transfers or transitions between hospitals or wards (e.g. Hawthorne & Killen, 2006).

Transition is a multidimensional concept that is difficult to describe (Boykova & Kenner, 2012). Kralik, Visentin and Van Loon's (2006) literature review of transition within healthcare found that the term often describes a process of change involving psychological processing to adapt to an event, such as illness or becoming a parent, rather than a return to

a pre-existing state. This implies that people have to find new ways of being in a changed environment or circumstance. Nyström and Öhrling's (2004) literature review of 33 studies, exploring the first year of parenthood, found that mothers and fathers entered into a new and overwhelming stage of life. Alongside feelings of love, pride and satisfaction gained from becoming a parent, mothers also experienced great physical and emotional strain, an overwhelming sense of responsibility and struggled to feel confident in their new role. Fathers were reported to have a similar overall experience of strain and significant change, while also thinking their role was to protect and provide for their partner and infant (Nyström & Öhrling, 2004). Boykova and Kenner's (2012) review emphasised that transition in itself can be a challenging process, and that parents of preterm infants who are discharged to home have to make two major transitions simultaneously. Firstly, the transition to parenthood and, secondly, the transition from hospital to home. Parents of preterm infants may have greater difficulty adapting to parenthood due to complexities typically associated with preterm infants. The infants may remain at increased risk for the first year of life, be developmentally immature, have more difficult temperaments and problems establishing feeding and sleeping routines (Bakewell-Sachs & Gennaro, 2004). Furthermore, parents may be required to manage medications and physical healthcare activities, which may increase parental anxiety post-discharge (Bakewell-Sachs & Gennaro, 2004).

In a national survey in England (n=9442), parents reported the care and support provided following their infant's neonatal unit discharge was one of the least positive experiences of neonatal care (Howell & Graham, 2011). Furthermore, Olshtain-Mann and Auslander's (2008) cross-sectional study found parents of preterm infants had significantly higher stress levels and lower self-rated parental competence two months after NICU discharge than non-matched control parents of full-term infants. These findings indicate that reviewing and summarising the literature about parents' experience of infant discharge could have potential benefits to infants and their families, and that highlighting the most pertinent concerns or stressors for families may enable services to adapt to their needs. The exploration and summary of service users' experiences is consistent with the current emphasis on patient-centred outcomes research (Phillips-Pula, Pickler, McGrath, Brown & Dusing, 2013) in healthcare settings and the drive to incorporate patient feedback into service design (Scottish Executive, 2006).

Qualitative methods are increasingly employed in healthcare research to gain a greater understanding of people's experiences of particular illnesses, treatments or service involvement. Systematic reviews and synthesis of qualitative research findings are utilised to enhance knowledge and generate theories that are more comprehensive and generalizable (Atkins et al., 2008). Previous reviews of parental experiences following discharge from NICU include Murdoch and Franck's (2012) systematic review of five qualitative studies. The review identified the following themes: parents' sense of new responsibilities; difficulties interpreting infant needs; seeking infant normalcy and the need for psychosocial and physical support in infant care. This review highlighted common themes across the studies, but did not conduct a meta-synthesis or rate the quality of the included studies. Additionally, a meta-synthesis by Swartz (2005) of ten qualitative studies on parenting preterm infants following hospital discharge identified five themes: adapting to risk; protecting fragility; preserving the family; compensating for the past and cautiously affirming the future. Murdoch and Franck (2012) and Swartz (2005) included different studies, except one (Jackson, Ternstedt & Schollin, 2003), which appeared in both. The current qualitative systematic review and meta-ethnography will update the meta-synthesis of parents' lived experiences of the post-NICU discharge period by Swartz (2005). An update will be helpful, as post-discharge care has been rated the least positive part of neonatal care by parents (Howell & Graham, 2011) and six relevant qualitative studies have been published since then. The studies in Swartz (2005) did not have their quality appraised, were published between 1990 and 2003, and may not fully reflect the increased prevalence of family-centred care in NICUs since 2001 (Gooding et al., 2011). Family-centred care is an approach to medical care founded on the belief that optimal health outcomes are achieved when patients' family members play an active role in providing emotional, social, and developmental support (Gooding et al., 2011).

Objectives

How do parents experience the transition of their infant from the NICU to home? What are the difficulties or challenges associated with transition to home and parenthood beyond the NICU?

Methodology

Search Strategy

A systematic search of the following electronic databases was completed between April and June 2014: Medline (OVID), CINAHL (EBSCO), Psychinfo (EBSCO), Embase (Ovid), and Web of Science. Searches of Google Scholar, the Cochrane Database (neonatal care, pregnancy and childbirth) and hand searches of the Journal of Obstetric, Gynecologic, and Neonatal Nursing and the Journal of Reproductive and Infant Psychology were completed. The reference lists of included studies were also searched.

Boolean operators (OR and AND) were used to combine search strings. Subject heading searches and keyword searches using the following terms were run:

1: parent* experience* OR mother* experience* OR father* experience* OR parent* narrative* OR parent* account* OR parent* lived experience*

AND

2: transfer OR transition* OR discharge* OR going home

AND

3: NICU OR Neonatal Intensive Care Unit OR SCBU OR Special Care Baby Unit OR newborn

AND

4: Qualitative method* OR Qualitative research

Inclusion criteria:

- Peer-reviewed journal publication
- Written in English
- Qualitative research presenting original data
- Article focused on the experiences of parents whose infant had been discharged from NICU, rather than a particular aspect of care, e.g. breastfeeding or an intervention
- Data from the pre- and post-discharge periods must be clearly differentiated

Exclusion criteria:

- Articles published prior to or included in the meta-ethnography by Swartz (2005)

Quality Rating Strategy

Studies eligible for inclusion had their quality appraised, as methodologically flawed studies could impact the findings (Walsh & Downe, 2006). Walsh and Downe (2006) recommend applying rigorous selection criteria and the use of quality criteria to evaluate studies prior to inclusion in a meta-synthesis. Yet, the application of quality criteria to qualitative research has been questioned, particularly as qualitative research often uses varying methodologies (Atkins et al., 2008; Dixon-Woods, Shaw, Agarwal & Smith, 2004). Walsh and Downe (2006) developed a checklist to evaluate the quality of qualitative research by reviewing and combining relevant items from existing frameworks. Atkins et al. (2008) highlight that the reporting of qualitative studies is often not as thorough as required to determine quality, unless it is published in a specific qualitative research journal. Consequently, a poorly reported yet methodologically sound study and a methodologically flawed study could both score poorly on a quality rating scale.

Each article was evaluated against a 12 item rating scale based upon Walsh and Downe's (2006) quality rating framework (Appendix 2). For each item, the article was allocated a 0 if the item was not present or not possible to determine based on the information provided, a 1 if the criteria were partially met or a 2 if they were fully met. Therefore, the maximum score available was 24. An independent reviewer rated the articles using the same scale blind to the researcher's initial ratings. The level of agreement was 94% and differences were resolved through discussion.

Synthesis

The synthesis of qualitative research is commonly termed meta-synthesis. Meta-ethnography is a type of meta-synthesis and was chosen for this systematic review as it facilitates the synthesis of research studies that use a variety of qualitative methods (Ring, Ritchie, Mandara & Jepson, 2011). Noblit and Hare (1988) developed meta-ethnography and outlined the seven-step process it entails (Table 1). Themes were compared across studies to determine the most dominant factors allowing the most prominent themes to be explored and resulting in a better understanding of parents' experiences.

Table 1. Stages of meta-ethnography (Noblit & Hare, 1988)

Stages	Description
Getting started	Determine research question
Deciding what is relevant to the initial interest	Defining the focus of the synthesis Locating relevant studies Making decisions about inclusion Quality assessment
Reading the studies and extracting data	Become familiar with the content and detail Begin to extract 'metaphors' or emerging themes
Determining how studies are related	Create a list of themes and metaphors Juxtaposition of above Determine how themes are related Reduce themes to relevant categories
Translating studies into one another	Arrange papers chronologically Compare paper 1 with paper 2, and the synthesis of these papers with paper 3 and so on
Synthesising translations	Third order interpretation leading to a line of argument synthesis
Expressing the synthesis	Presentation of results Publication of findings

Results

Systematic search results

The database search yielded 168 articles. The Google Scholar search identified 21 articles and hand searches of two journals identified two articles; of these 23 articles, those that were eligible for inclusion had all been identified during the database search. Duplicates were removed (n=14) and the title or abstract of the remaining articles were screened for relevance, resulting in the removal of 131 articles. Forty-six full text articles were examined according to the inclusion and exclusion criteria, which excluded a further 41 articles. This resulted in five eligible articles; one further article was identified through reviewing the reference sections of included articles (Figure 1).

Quality rating results

Six articles included in the meta-synthesis were rated using Walsh and Downe's (2006) quality criteria. All articles achieved a rating of 'good' or 'acceptable' quality (Table 2). The articles rated as acceptable (Flacking, Ewald & Starrin, 2007; Griffin & Pickler, 2011) were included due to their relevance to the meta-synthesis and because they demonstrated 11 of the 12 essential criteria described by Walsh and Downe (2006). The essential criteria that neither article demonstrated was researcher reflexivity; Walsh and Downe (2006) acknowledge that many published qualitative articles do not include reflexivity as a consequence of word restrictions imposed by journals.

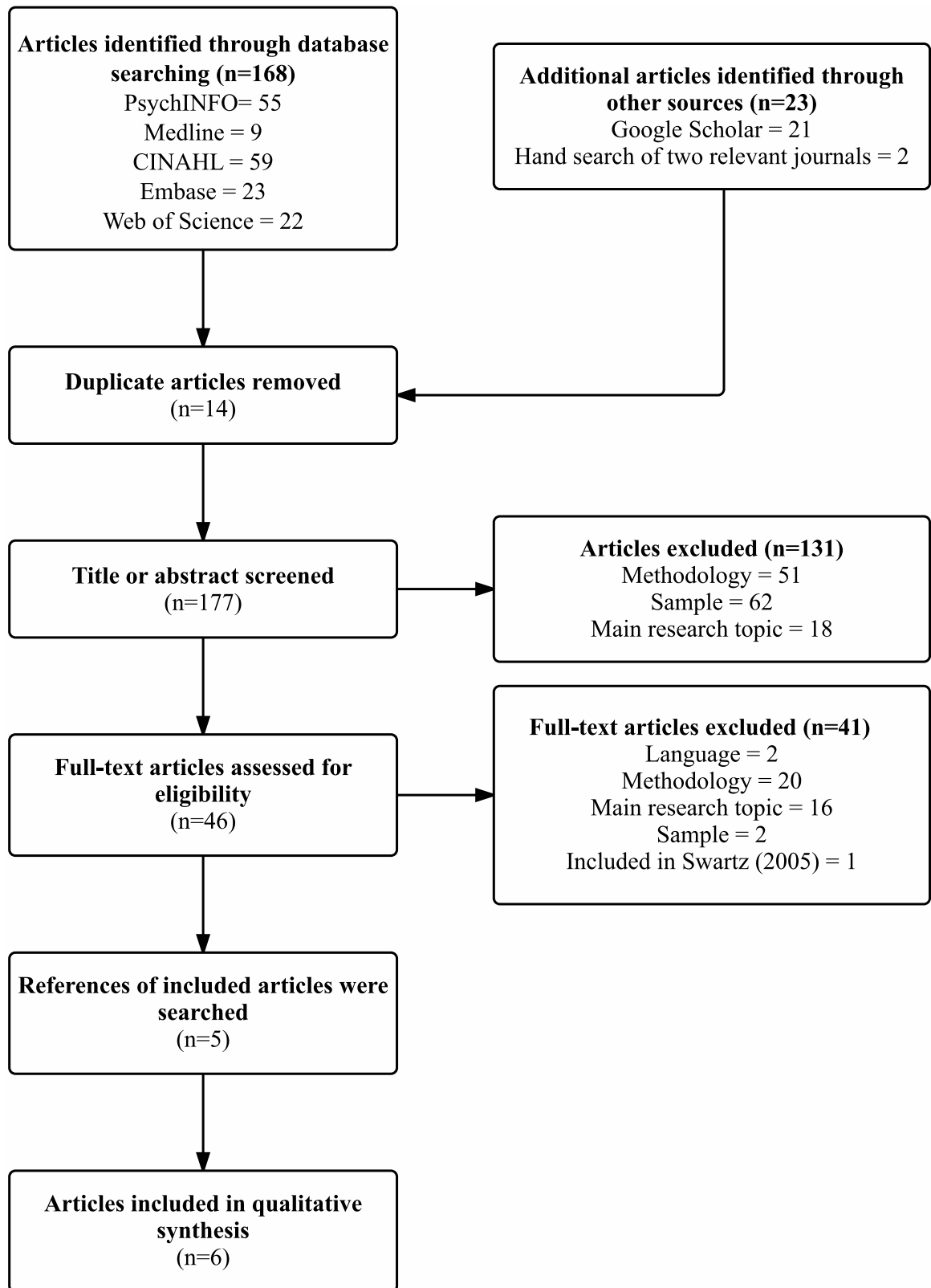


Figure 1. Flowchart of search results

Table 2. Summary and quality rating scores of articles, N = 6

Study (Year) Country	Participants	Method	Aim	Quality rating & category
Lundqvist et al. (2014) Sweden	Fathers (n=8) of preterm infants.	Interviews conducted 3 years post-discharge. Hermeneutic phenomenology.	To describe fathers' lived experiences since their infant's birth and NICU discharge.	91.6% Good
Phillips-Pula et al. (2013) USA	Mothers (n=8) of preterm infants.	Interviews conducted 1-6 months post-discharge. Transcendental phenomenology.	To examine the experiences of mothers following NICU discharge.	95.8% Good
Murdock & Franck (2012) UK	Mothers (n=9) of term and preterm infants.	Interviews conducted 3-15 months post-discharge. Descriptive phenomenology.	To describe mothers' experiences of caring for their infant following NICU discharge, including, pain management.	83.3% Good
Griffin & Pickler (2011) USA	Mothers (n=10) of preterm infants.	Interviews conducted 2-4 weeks post-discharge. Descriptive phenomenology.	To understand and describe the maternal experience following NICU discharge.	66.7% Acceptable
Nicolaou et al. (2009) UK	Mothers (n=20) of preterm infants.	Interviews conducted post-discharge when infants were 4-24 months old. Thematic analysis.	To explore mothers' experiences of early interactions and their perceived support and information needs after NICU discharge.	87.5% Good
Flacking, Ewald & Starrin (2007) Sweden	Mothers (n=25) of very preterm infants.	Interviews conducted 1-12 months post-discharge. Grounded theory.	To explore how mothers experience becoming a mother and breastfeeding their infants after NICU discharge.	58.3% Acceptable

Note: NICU = Neonatal Intensive Care Unit

Synthesis

Themes identified in the selected articles are provided in Table 3. Through the meta-ethnography, a new interpretation of the dominant themes was developed. This process identified six key themes arising from parents' experiences of their infants discharge from NICU:

1. Mixed emotional response
2. Overwhelming sense of responsibility
3. Commitment
4. Hope for the future
5. Developing the parental role
6. Changed perspective

Each theme will be discussed in turn with quotations from parents in the original articles in italics. Square brackets indicate an omission or addition to the original text - made by either the original authors or for the purpose of this review - to provide greater focus or to increase the readers understanding.

Table 3. Themes from the articles included in the meta-ethnography

Study (Year)	Themes/Findings
Lundqvist et al., (2014)	Key theme of reorganising life. Three subthemes <ol style="list-style-type: none">1. Initially following discharge they struggled to endure;2. Then they began to experience empowerment;3. Finally, in the present they could build a secure base.
Phillips-Pula et al., (2013)	Mothers described the time following discharge as the most difficult of their lives. <ol style="list-style-type: none">1. Fear of the unknown2. Exhaustion3. Determination4. Thankfulness
Murdoch & Franck, (2012)	<ol style="list-style-type: none">1. Apprehension - about infant's fragile health, loss of medical team and performing procedures

	<ol style="list-style-type: none"> 2. Confidence – grew as health improved 3. Responsibility – for performing medical procedures 4. Awareness – of infant needs especially pain 5. Normalcy – searching for 6. Perspective – time enabled positive interpretation of their experience
Griffin & Pickler, (2011)	<ol style="list-style-type: none"> 1. Dealing with an unexpected pregnancy outcome 2. Experiencing the reality of taking care of the baby alone 3. Struggling to adjust to the maternal role 4. Enhancing maternal inner strength 5. Changing the maternal lifestyle
Nicolaou et al., (2009)	<ol style="list-style-type: none"> 1. Anxiety regarding transition from hospital to home 2. Preparation for discharge emphasised information regarding medical items rather than interaction 3. Parental insecurity about interacting with baby 4. Sleepy baby/unresponsive baby 5. Interactions improve with time 6. Unfulfilling support from health visitors
Flacking et al., (2007)	<p>The mothers' experience of becoming a mother and breastfeeding fluctuated with changes in:</p> <ol style="list-style-type: none"> 1. emotional state (between exhaustion and relief); 2. maternal-infant bond (between secure and insecure); 3. experience of breastfeeding (between non-reciprocal and reciprocal)

Mixed emotional response

Parents' emotional responses following the discharge of their infant from the NICU were variable, including both strong positive and negative emotions and frequently a combination of both - with pleasure, happiness, relief and anxiety frequently being reported simultaneously.

“I was completely elated and very happy, followed by absolute fear and terror.”

(Nicolaou et al., 2009, p.187)

For parents the discharge to home was a significant moment, indeed it was described as ‘the best moment’ by mothers in Griffin and Pickler’s article (2011). Parents expressed pleasure at the time of discharge and that this event was of great significance to them; discharge represented the achievement of something that some had feared might not transpire due to the severity of their infant’s illness.

“It was just really lovely, you know, after everything, we had been through, there were times we never thought we would take him home, and um so to take him home was lovely.” (Murdoch & Franck, 2012, p.2017)

“That morning when we went home, it felt almost as if he was just born at that time. It sounds weird, but the day he was born was not as important as the day we went home. It felt as we had managed it and that we were on our way home.” (Flacking et al., 2007, p.2408)

All studies reported that parents felt anxiety about their infant’s discharge home. Parental anxieties typically related to concern about their infant’s health, uncertainty about what it would be like to care for their infant at home and whether they would be able to cope with these demands. Parental anxieties were greatest in the initial post-discharge period and continued to be present for up to six months later (Phillips-Pula et al., 2013). Due to differences in methodology and reporting it was not possible to determine whether a common time frame exists for when a reduction in parental anxiety about their infant’s health or their ability to care for them occurs.

“I would get nervous about absolutely everything, [...] if he didn’t eat, because he wasn’t eating, if he ate too much, because he ate too much. If he slept too much I worried that something would happen to him.” (Murdoch & Franck, 2012, p.2013)

One article suggested that parents might sometimes be unrealistic about the demands that they will experience following their infant’s discharge from NICU, focusing instead on their joy and relief (Phillips-Pula et al., 2013). Yet, most parents approached discharge with feelings of apprehension and anxiety, indicating insight into how difficult discharge might be. Nonetheless, it may not be possible for parents to fully comprehend the reality of taking an infant home from NICU prior to doing so.

Articles described parents' exhaustion in the post-discharge period (Flacking et al., 2007; Griffin & Pickler, 2011; Lundqvist et al., 2014; Phillips-Pula et al., 2013). A protracted NICU admission can be tiring for parents, due to the emotional and physical demands encountered. Consequently, parents may be exhausted prior to taking their infant home. At home, parents need to provide regular day and night care for their infant, some of which would previously have been completed by NICU staff. Furthermore, infants who have been in NICU are likely to require extra appointments, monitoring and care to ensure on-going medical needs are met, which may have a greater impact on parents' tiredness.

"I just know I got to do it I got [to] stay woke with him because he's my child."
(Griffin & Pickler, 2011, p.255)

Exhaustion may lead to parents struggling to adapt to new parental duties and adversely impact on their relationship with their partner, family and infant. Significant relationship strain was reported in two studies (Lundqvist et al., 2014, Phillips-Pula et al., 2013) where parents acknowledged they were short tempered and "at each other's throats" (Phillips-Pula et al., 2013, p.339). The following quotation demonstrates one contributory factor to parents' exhaustion, with this parent describing how their anxiety and subsequent need to check her infant's wellbeing significantly impacted on her sleep.

"Even when sleeping becomes a little easier you still wake up in a panic and need to run and check on [her] because you've slept for a while and you don't know what's happened." (Phillips-Pula et al., 2013, p.339)

Overwhelming sense of responsibility

At the time of discharge parents felt an overwhelming sense of responsibility for taking care of their infant. In particular, parents felt anxious about taking responsibility for the monitoring and administration of their infant's medical care, which had previously been completed by specialist equipment and trained medical professionals.

"At first I was too scared to take a shower...if I didn't hear her, how would I know she was still breathing or that her heart hadn't stopped? It's still there [fear] even after four months." (Phillips-Pula et al., 2013, p.339)

The loss of trained medical staff was a substantial factor that added to parental anxiety about discharge from NICU. Frequently parents did not believe that they had the necessary capacity or skill to be the sole care providers for their infants, particularly when they took on medical care activities, including, insertion of nasogastric feeding tubes, colostomy care, use of supplemental oxygen and bowel washouts.

“You can look at them and sort of squeak for help and help arrives pretty quickly. Whereas suddenly there’s this feeling that you’re out there on your own really.”
(Nicolaou et al., 2009, p.187)

Parents in two studies (Lundqvist et al., 2014; Murdoch & Franck, 2012) explicitly referred to the medical procedures that they completed following discharge. For some families, taking responsibility for health care procedures allowed their infant to be discharged home earlier. The following quotation describes a father’s experience of being responsible for inserting a nasogastric feeding tube into his infant, he considered it an unpleasant but essential part of caring for his infant:

“It was necessary, so it was just a matter of grin and bear it. But it’s no fun.”
(Lundqvist et al., 2014, p.127)

Another parent spoke about their sense of responsibility and anxiety associated with performing a medical procedure at home.

“If [we] weren’t getting these bowel washouts right the baby would have problems [...] we were really anxious for about the first week of him being home.” (Murdoch & Franck, 2012, p.2014)

Parents frequently checked their infants to reassure themselves that their infant remained well and reduce their anxiety about taking on greater caregiving responsibility. Some parents sought reassurance from health professionals regarding their infants’ development and others kept records that logged observable and measurable change to provide themselves with irrefutable evidence that their infant was receiving the care they required:

“I still keep a little diary of everything he has and, just to sort of reassure myself that he is getting enough and he is having regular feeds, and um, and I guess just watching the weight go on is reassuring because I realize he is obviously getting enough feed, but clearly he is because he is putting on weight, so yes it is going well.” (Murdoch & Franck, 2012, p.2015)

The measurement of their infant’s development and the passing of time allowed parents to gain confidence in their ability to manage their infant’s care.

“I do think initially when she came home it did take a long time, not long but it did take a few weeks for me to trust myself and what I was doing was good enough.” (Murdoch & Franck, 2012, p.2013)

In all but one study (Flacking et al., 2007), parents spoke about the preparation they received prior to discharge; yet despite this, parents did not feel completely prepared for their infant’s discharge. In Murdoch and Franck (2012), mothers reported that acquisition of knowledge and information relevant to their experience served to reduce their anxiety. Mothers sought information from a number of external sources, including family members, professionals, books, and the internet. Some parents reported feeling well prepared in a particular aspect of care, for example feeding, however, parents in Nicolaou et al. (2009) reported that they would prefer more holistic preparation for discharge including: information about protecting their infant’s health; suitable toys; developmental play and milestones and how they might differ for infants born prematurely.

“We were given preparation but it was all very medical. We had booklets and discussions about RSV [Respiratory Syncytial Virus], meningitis, all the things he could pick up, but in terms of how to actually care for him and what to do when we got home there really wasn’t anything.” (Nicolaou et al., 2009, p.188)

Most mothers in Nicolaou et al.’s (2009) study (14/20) reported dissatisfaction with the lack of information provided about interacting with their babies. However, in this study parents were asked specifically about their experience of information provision. Nonetheless, the theme of feeling ill-prepared for discharge was also identified in four of

the other studies (Griffin & Pickler, 2011; Lundqvist et al., 2014; Murdoch & Franck, 2012; Phillips-Pula et al., 2013).

“It was really scary at first, it was my first baby, I only had one night on the neonatal unit before they discharged her, so that kind of didn’t really prepare me for what it was going to be like with just me at home.” (Murdoch & Franck, 2012, p.2014)

Perceived lack of preparation impacted on parents’ anxiety about discharge and their confidence in their ability to care for their children. The articles in this review represent countries in which family-centred care is typically practiced within NICUs. Family-centred care encourages parental involvement in infant care, yet the mother quoted above felt the time allocated to develop confidence in caring for her infant was insufficient. Fathers reported they were prepared for discharge, but had not been fully prepared for the reality of taking on full caring responsibility for their infant; fathers felt this regardless of how much of their infant’s care they had been involved in during their infant’s NICU admission (Lundqvist et al., 2014).

Commitment

Parents in all articles demonstrated their commitment to caring for their infant including the provision of protection and ensuring that medical and social needs were met. For some parents there was a conscious realisation and admission of their intent to prioritise their infant’s care:

“It may take one or two years of isolation, but that’s not important just now. If we can have a healthy Harry, that’s much more important.” (Flacking et al., 2007, p.2410)

This parent demonstrates a long-term commitment to prioritising her infant and is willing to put her infant’s needs first, to ensure that he is healthy and has the best outcome. Other parents demonstrated commitment by making lifestyle changes to ensure that they were capable of caring for their child whilst maintaining other responsibilities and interests, which frequently came second to providing care for their infant. Parents expressed their commitment to protecting their infants from future illness:

“You can look all day long but don’t touch. Don’t cough on my baby or we gonna have some problems.” (Griffin & Pickler, 2011, p.255)

This mother spoke about her concerns when introducing her infant to family and friends. She strongly advocated that others should not touch her infant and those who did were required to wash their hands prior to doing so. This mother’s desire to protect her infant from viruses or contamination took precedence over fear that she may be upsetting others and her relationships with them. Fathers also reported prioritising their infant over other relationships; they spoke about the negative impact this had on their relationship with their partner initially and the sacrifices they made to their lifestyle to accommodate their child (Lundqvist et al., 2014).

Parents also spoke about their commitment to helping their child’s development, with one mother asserting:

“She [is] gonna do those things [be] cause I’m going to make sure she does them.”
(Phillips-Pula 2013, p.340)

This quotation demonstrates a mother’s response to her infant struggling in a physical therapy session and her subsequent desire for her infant to be supported to achieve what she can. It is possible that parents of ill or preterm infants may feel guilt or shame about their infant’s illness or premature birth and that this may be a motivating factor that encourages commitment to supporting their infant (Flacking et al., 2007).

“If I have him inside my dressing gown and he’s skin-to-skin ... it’s a compensation for him for having had such a tough start.” (Flacking et al., 2007, p.2410)

Hope for the future

Parental concern about their infant’s future health was reported in all but one of the studies (Nicolaou et al., 2009). Parents were particularly concerned about their infant meeting appropriate developmental milestones (Lundqvist et al., 2014; Murdoch & Franck, 2012; Phillips-Pula et al., 2013). This continuing concern regarding potential developmental delays led to parents frequently comparing their infant with other infants whom they considered to be healthy or normal:

“It’s really difficult not to compare with others who are the same age. Although everybody says you shouldn’t compare, that everyone is different, you can’t help doing it, you want what’s best for your children.” (Lundqvist et al., 2014, p.127)

This father acknowledges that it is difficult not to compare his infant to others and that the consequences of doing this could be unpleasant as it may highlight that his child is not developing as expected. The following quotation demonstrates that making comparisons with other infants can have a favourable outcome. This mother was comforted that her baby could be perceived as ‘normal’ given their difficult start to life and the potential adverse consequences of prematurity, such as developmental delays. Parents hoped that their baby may become or appear normal (Flacking et al., 2007; Lundqvist et al., 2014; Murdoch & Franck, 2012):

“We’ve got a few sort of friends [in the community] who just had babies, and [...] seeing them, and talking to them about their sort of normal baby made us think um that actually [son] was doing similar things, so he must be, you know, normal as it was.” (Murdoch & Franck, 2012, p.2013)

The following quotation highlights that parents’ perceptions of normal are altered during NICU admission. Parents became accustomed to the NICU environment and other infants and parents in the ward; at discharge they left an environment that knew and understood them and their preterm infant. At home they were not surrounded by other families with similar experiences to them, which may have seemed strange, and was perceived by parents to indicate that they or their infant were abnormal:

“When you are in hospital you are kind of in this world that is you are all in it together [...] all the people you made friends with, they all are just they understand what you are going through [...] but when you come out into a wider world, I think that was quite odd because all of a sudden you are not like every mother.” (Murdoch & Franck, 2012, p.2016)

Developing the parental role

The discharge of an infant from NICU leads to a change in the parental role and family life, with parents assuming greater responsibility for their infant’s care. Greater involvement in caregiving was associated with an increased sense of parental role and

development of the attachment relationship. Discharge enables parents to engage in typical activities that they would have done if their infant had not required admission to NICU. Discharge to home led to parents feeling more able to take ownership of their parental role as they gained greater control when they acquired responsibility for their infant's care. Unlike when their infant was in NICU, parents were able to develop their own routine at home, which led to them feeling greater security in their relationship and like the infant was theirs:

"We had to ask if we wanted to hold her, or change her nappy, or do anything. So it didn't really feel like she was ours." (Nicolaou et al., 2009, p.186)

Parents' relationships with their infants developed over time through increased interactions or their infant showing a preference for them. Parents reported enjoying and feeling proud of their parental role and that being able to meet the infant's needs was perceived as satisfying:

"He's very attached to me. He only looks at me. It feels as if we have something special." (Flacking et al., 2007, p.2410)

"My husband tried the bottle once but it's me he wants...that feels good." (Flacking et al., 2007, p.2413)

The passing of time led to improved infant health and development, including increased alertness and interaction, which consequently led to parents experiencing increased confidence in their parental role (Murdoch & Franck, 2012; Nicolaou et al., 2009; Phillips-Pula et al., 2013). Some parents expressed their desire for a more reciprocal relationship with their infant and their frustration about the lack of such a relationship:

"I've given so much ...and these months have been so hard... so you start to feel that you want something back [...] it has taken such a long time to understand that he's mine. I will feel 100% happy when he's happy to hear me." (Flacking et al., 2007, p.2410)

Fathers also felt their parental role gradually matured and that it was essential for them to be ‘a manifest and important person in their infant’s life’ (Lundqvist et al., 2014, p.127). The fathers felt happiness when they realised that their infant needed them and they were able to enjoy one another’s company. At three years post-discharge one father stated:

“We do a lot of things together, watch drag racing, and things like that, he’s really interested in that.” (Lundqvist et al., 2014, p.128)

Flacking et al.’s (2007) study in particular reported that some mothers struggled to develop the mother-infant relationship and their maternal role. They identified that the separation from their infant and the infant’s frequent contact with numerous staff had impacted on their sense of purpose, parental identity and confidence - fostering a sense that their role could be fulfilled equally as well by someone else:

“I think that you’re used to leaving them in a different way when they’ve been at a unit for such a long time as they have. Because then you leave them every night to someone....so you’re used to other people taking care of them, even if they don’t do it as we do. I can leave them with my sister or my mum. It will be OK either way.” (Flacking et al., 2007, p.2409)

Discharge of an infant from the NICU required parents to manage competing demands and adjust their pre-existing lifestyle and relationships. For some parents this involved adapting their relationship with their partner by moving from being a couple to a family and for some families helping their older children adapt to another child being at home:

“It’s been just me and him [husband] for so long and to have another person to think about – that’s completely different...I haven’t figured it out yet.” (Griffin & Pickler, 2011, p.255)

Fathers spoke about their duty to support their partners, which they perceived as a significant part of their role. Lundqvist et al. (2014) was the only study in this meta-synthesis that investigated fathers’ experiences of their infant’s discharge from NICU. Mothers in the other studies reported that their husbands or partners provided enormous

support to them, yet none of the articles presented information about mothers providing support to their partners.

Parents frequently spoke about the valuable support they received from family, friends and professionals. Parents acknowledged that this support enabled them to strengthen and develop confidence in their parental role following discharge. Parents described the positive impact this support had on their wellbeing and ability to cope with their stressful situation (Flacking et al., 2007; Griffin & Pickler, 2011; Murdoch & Franck, 2012):

“I would tell my husband, I would go on and talk to him and just vent and let it all out [...] and that’s helped.” (Griffin & Pickler, 2011, p.256)

Mothers appreciated support from partners’ as it allowed them time and energy to focus on completing care activities and developing their relationship with their infant. This was also true of support received from grandparents and extended families:

“Because we had people here to take care of us [parents], we could then concentrate on taking care of her.” (Murdoch & Franck, 2012, p.2015)

Unfortunately, parents reported some instances when contact with family and friends was not helpful. This occurred when parents felt unsupported by individuals who did not understand or have experience of having an ill or premature infant:

“I don’t care how many friends you have and how many babies they’ve had, if you didn’t have a baby in the NICU, you don’t get it.” (Phillips-Pula et al., 2013, p.340)

“Just because one is home, everyone said: ‘But Sara, doesn’t it feel good? Isn’t it glorious to be a mom!?’ I think that’s criminal! Because that’s not how you feel. In fact, it’s only now, in the last month, that I can feel the real thing...that it’s us two and how fond I am of her. It has taken a really long time. You hardly dare to say it.” (Flacking et al., 2007, p.2408)

In the above quotation, differences between this mother’s experience and societal or family expectations led to her feeling guilt, shame and anger that she was not coping or reacting in

the way that others expected her to. Another mother also described that professionals in the community did not always provide effective support:

“The health visitors have been very sweet but they quite often have very little idea about practical issues with premature babies. Sometimes you feel abandoned.”
(Nicolaou et al., 2009, p.190)

In only one study (Phillips-Pula et al., 2013) was the use of a formalised support group available for parents. However, mothers in two other studies believed there would be particular value to having a support group led by parents who had had a similar experience (Murdoch & Franck, 2012; Nicolaou et al., 2009).

Changed perspective

Parents described a change in perspective or priorities as a consequence of their experience of having an infant who required care in a NICU (Griffin & Pickler, 2011; Lundqvist et al., 2014; Murdoch & Franck, 2012; Phillips-Pula et al., 2013):

“Things that you thought were important don’t mean anything...he’s my concern right now. I don’t care about anything else that goes on around me.” (Griffin & Pickler, 2011, p.256)

Another parent spoke about how an infant they had known in NICU had died and how this had prompted her to reflect on how grateful she was about her own infant’s survival. This mother was more accepting of difficulties and stresses as she knew that her infant was alive, which was ultimately the most important thing:

“I went to a funeral yesterday for one of the babies that was born just before them, you know and he didn’t make it. I just think whatever problems [son] has, he is here and that’s all that matters. I think that puts everything into perspective and makes you think well that is all that really counts isn’t it.” (Murdoch & Franck, 2012, p.2013)

From surviving the challenges of having an infant who requires admission to a NICU parents reported personal growth, including gaining strength and confidence in their ability to face future challenges:

“I mean if you can manage that, you can manage much more.” (Lundqvist et al., 2014, p.128)

Discussion

This review synthesised qualitative research about parents’ experiences of their infant’s discharge from NICU to home to facilitate a greater understanding of their experience. Six themes were identified through the meta-synthesis: mixed emotional response; overwhelming sense of responsibility; commitment; hope for the future; developing the parental role and changed perspective.

This review found that parents often experience the time following their infant’s discharge from NICU to home as filled with intense and changeable emotions. This is consistent with previous qualitative studies that explored parents’ post-NICU discharge experiences, such as Garel, Dardennes and Blondel (2006) and Jackson et al. (2003); these studies were excluded from the current review for only publishing a selection of the themes identified in interviews and for being included in Swartz (2005), respectively. The parental experience reported in this review is broadly similar to that of parents of healthy infants who also experience the initial time at home with their infant as emotionally challenging (Nelson, 2003), indeed Nyström & Öhring (2004) described this period as ‘living in a new and overwhelming world’ (p.324). However, NICU families are likely to experience distress and stress to a greater extent than families with healthy infants who do not require NICU admission. This is due to factors such as a complicated pregnancy and delivery; unresolved neonatal health conditions and concerns about the infant’s future development (McKim, 1995; Obeidat et al., 2009; Zanardo, Freato & Zacchello, 2003). Davis, Edwards, Mohay and Wollin (2003) found rates of depression amongst mothers of preterm infants were 40% compared to 10% in mothers of healthy infants at one month after birth. Similarly, mothers of NICU infants have been found to have significantly higher anxiety than mothers of healthy infants following hospital discharge (Zanardo et al., 2003). Psychological distress can have a negative impact on mothers’ ability to relate to their infant and consequently on the child’s development (Garel, Dardennes & Blondel, 2006). In the current review

parental exhaustion and fear were particularly prevalent in the immediate post-discharge period; this is similar to the experiences typically reported by parents of healthy infants (Nyström & Öhrling, 2004) as they adapt to providing regular care for their infant. NICU parents report similar experiences and concerns as parents of healthy infants; however, they are likely to experience them more intensely, which may impact on the development of their parental role and parent-infant relationship.

This review found that parents' emotional response to the discharge of their infant was characterised by high levels of anxiety about assuming primary responsibility for the care of their infants - particularly in relation to the completion of medical procedures. This finding is similar to the theme entitled 'adapting to risk' identified in Swartz (2005), which described parents' overwhelming concern regarding their infant's health and development. In the current review, parents reported that preparation for going home had occurred prior to their infant's discharge, however, it was often perceived as lacking due to being too brief or not including all aspects of care. It is possible that parents' anxiety about completing infant care or medical tasks could be reduced by more suitable information-giving practices. Phillips-Pula et al. (2013) suggest that maternal anxiety in NICU and particularly prior to discharge may impact on mothers' abilities to take in the necessary instructions, which may have subsequently reduced their anxiety about completing the tasks once home. This is consistent with literature that suggests that memory of medical information is adversely affected by high levels of anxiety and distress (Kessels, 2003). Furthermore, information recall is state-dependent (Kessels, 2003), with information learned in a stressful environment better recalled in a similar environment, thus if parents learn information in a stressful ward environment their recall will be poorer at home despite being more relaxed. If parents' capacity to retain information provided in the ward were compromised it would be beneficial to consider how staff can maximise carry-over of information to reduce parental anxiety once home. Strategies to improve carry-over of information may include, for example, simplification and repetition of information and the provision of a written or pictorial summary of the procedure (Kessels, 2003).

Parents demonstrated incredible commitment to providing care for their infants, giving them priority over relationships or responsibilities that had previously taken precedence. Nelson (2003) reviewed the transition to motherhood in mothers of predominantly healthy infants and found that mothers must commit to actively engage with the process of

mothering and strive to adapt to the mothering role to enable growth and transformation. Parents in the current review demonstrated their desire to protect and support the development of their infant, with some studies indicating that parental guilt and shame about their infant's ill health or prematurity may have motivated them to compensate for their infants difficult start in life (for example, Flacking et al., 2007). This finding is consistent with research demonstrating that mothers of prematurely born children attempt to compensate for their infants early experiences up to three years later (Miles & Holditch-Davis, 1995). Compensatory parenting styles differ in terms of the provision of increased protection, stimulation, attention and more lenient limit-setting (Miles & Holditch-Davis, 1995). Swartz (2005) also described that parents' of NICU infants aimed to protect their infants and adapted their parenting style to compensate for the past in the themes entitled 'protecting fragility' and 'compensating for the past', respectively. The articles included in the current review and those in Swartz (2005) collected data at similar time periods following discharge, despite this 'compensating for the past' did not emerge as a predominant theme; this may be because different articles were included in the meta-synthesis or due to increased professional knowledge about the longer-term impact of prematurity on infant development and family functioning.

In the current review, parents expressed hope for their infant's future, which appeared to be linked to their concern that their infant may have developmental delays or difficulties that emerge over time. Parents also hoped that their infant could be considered 'normal' despite their complicated start to life. The majority of parents in this review were parents of premature infants who are known to be at greater risk of cognitive impairment, language difficulties and neurodevelopmental difficulties, including: cerebral palsy, or hearing or visual impairments (Moore et al., 2012). As such, it is unsurprising that parents may be concerned about potential long-term consequences for their children. In this review parents described discharge as a significant moment that indicated that their infant had survived, which some had feared might not happen. Therefore, it seems likely that discharge signifies a change in parental focus from infant survival to their infant's future health and quality of life. This theme in the current review entitled 'hope for the future' is similar to 'cautiously affirming the future' in Swartz (2005), which also included parental concerns about potential long-term difficulties alongside a focus on developing reciprocal interactions with their infant that resulted in gratification and pleasure for parents (Swartz, 2005).

This meta-synthesis indicated that greater parental involvement in caregiving following infant discharge from NICU was associated with an increased sense of parental role and development of the attachment relationship. This is consistent with qualitative research that has shown that mothers and fathers require physical proximity and involvement in care to develop their bond with their infant whilst in the NICU (Fegran et al., 2008; Wigert et al., 2006). This review found that parents' relationship with their infant took time to develop, which is consistent with literature relating to mothers of healthy infants (Nelson, 2003). However, it is recognised that having an infant in NICU often leads to a delay in developing the parental relationship (Fegran et al., 2008) and that discharge home can be challenging for NICU parents. Discharge is likely to be more challenging for these parents because they have to make an additional transition – not just to parenthood but also from the NICU to home (Boykova & Kenner, 2012). Parental stress and distress is greatest during an infant's admission to NICU and gradually decreases with time. Following discharge, parents have been found to appraise their situation as more controllable, less threatening and less stressful (Rowe & Jones, 2010). Increased parental control and involvement in their infant's care following discharge enables parents to further develop their caring role and provides additional opportunities to gain positive feedback, which improves their sense of parental efficacy. Parents' perceptions that they can meet their infant's needs increased their confidence and facilitated the developing attachment relationship. Another potential factor that influences the development of the parental role is that premature infants often give reduced signals to parents due to physical and developmental immaturity, consequently, as they develop they become more alert and interactive providing parents with the positive feedback that they desire (Flacking et al., 2007), which increases their sense of a reciprocal and rewarding parent-infant relationship.

In this review fathers perceived that they had a duty to support their partners following discharge from NICU (Lundqvist et al., 2014), which is consistent with existing qualitative literature that found fathers' identified the emotional support they provided to their partners as an important part within their new parental role (Bissell & Long, 2003). Overall, parents' reported that support from friends and family was valuable, including practical support, such as cooking and cleaning or looking after older children, as this enabled the parents to focus on providing care for their infant. Again this is similar to the experience of parents of healthy infants who placed great value on the advice and reassurance gained

from friends and family (Nelson, 2003). Parents of NICU infants particularly valued practical support provided by family and friends in addition to information and emotional supports. Parents may appreciate practical support to cope with the physical and emotional demands of having an infant in NICU for a prolonged time period and the demands associated with their infant's additional care needs (Bakewell-Sachs & Gennaro, 2004). Mothers in two studies (Flacking et al. 2007; Nicolaou et al., 2009) reportedly found some support from professionals in the community unhelpful, perhaps this is due to the relatively low proportion of infants born prematurely and consequently general practitioners and health visitors may not have the experience and knowledge that parents require (Broedsgaard & Wagner, 2005).

Following discharge, parents particularly lamented the loss of ward staff support; however, they also lost the support of other parents. Parents found speaking to other NICU parents helpful and comforting, as they were perceived to fully comprehend the parents' experiences and feelings as they were going through something similar themselves. Articles in this review indicate that peer support or buddying up with experienced NICU parents occurs infrequently, yet is something that parents consider a valuable resource (Gooding et al., 2011). Similarly, Swartz (2005) recommends that opportunities for peer support should be prioritised as this can reduce mothers' anxiety and depression.

The final theme identified in this review was 'changed perspective' which reflected changes in parents' priorities and outlook. When parents reviewed their experience of having an infant who required NICU admission they found aspects of the experience to be thankful for and identified that the experience had led to personal development and increased strength.

The meta-synthesis in Swartz (2005) of ten qualitative studies on parenting preterm infants following hospital discharge identified the following five themes: adapting to risk; protecting fragility; preserving the family; compensating for the past and cautiously affirming the future. Overall, the current review confirmed the findings of Swartz's review although there were some differences in the arrangement and content within the themes, as discussed within each theme above. This review identified developing the parental role as a key theme that was consistently raised in all studies. Swartz (2005) did not identify a specific theme about developing the parental role, although it could be argued that the five

themes identified in her review impact on the development of the parental role and the parent-infant relationship. A greater emphasis of this theme in the current review may have occurred purely due to the different articles reviewed, although the available participant and infant data across all studies in both meta-syntheses indicates that the reviews were based upon similar populations. Another factor that may have led to a greater emphasis on parental role development in the current review is that parents are increasingly encouraged to have greater involvement in their infant's care as part of the family-centred model of care adopted by NICUs (Gooding et al., 2011).

Reflexivity

The synthesis and interpretation of the research in this review is likely to have been influenced by the researcher's experience of working with parents of NICU infants. Furthermore, as a trainee Clinical Psychologist the researcher is influenced by their knowledge of psychological theories.

Limitations

There are a number of limitations to this current review that warrant exploration. Firstly, the themes identified in the review could extend to parents who have a healthy infant who does not require neonatal intensive care. However, there are a number of factors that differentiate the experience of parents of NICU infants compared to healthy infants, including the heightened emotional and physical impact of a protracted hospitalisation, increased anxiety about infant health and involvement in the provision of medical care. Furthermore, the development of the parental role and parent-infant relationship is often delayed in parents of NICU infants; therefore, the findings from this meta-synthesis take into account these additional challenges encountered by NICU parents during the transition to parenthood.

A further limitation is that there is likely to be a sampling bias in that parents who chose to take part in research may do so as they were motivated to share their experience, whereas those who chose not to participate may have had different experiences. The articles selected for this review were all conducted in Europe and North America; therefore, the results of the review may not reflect the experiences of parents from alternative geographical locations or cultural backgrounds. Additionally, only one article (Lundqvist

et al., 2014) explored the experiences of fathers, consequently the review may not be fully representative of fathers' experiences. In light of these biases it is important to acknowledge that the results of the current review are not entirely conclusive.

In the articles included in this meta-synthesis, interviews were conducted with parents between two weeks and three years post-discharge, and time passing is likely to influence the concerns parents have about their infant. Those interviewed at a later time might have had more time to reflect on their experience and gained greater confidence with providing infant care, developing their parental role. They may also have a clearer understanding about the likely future development and health of their child. Parents' perceptions of how stressful and threatening their situation is reduces within the first three months following NICU discharge (Rowe & Jones, 2010), therefore, it is likely that parents interviewed a number of years after discharge will report different concerns or experiences to parents who are more recently discharged. However, the inclusion of articles with differing time scales for the interviews was useful to gain insight into the longer-term experiences of parents following NICU discharge.

A challenge when completing the meta-synthesis was that some articles had specific research aims in addition to exploring parental experience post-NICU discharge. This meta-synthesis aimed to include articles that did not focus on a particular element of parental experience to the detriment of the topic of interest. Yet it is possible that the focus of some of the studies may have affected the interpretations made by the authors, for example, Flacking et al. (2007) aimed to explore breastfeeding and the process of becoming a mother. The current review aimed to incorporate these studies by using author interpretations of quotations and considering alternative interpretations, whilst maintaining the original context of quotations.

Implications

The review suggests that parents of infants who are discharged from the NICU experience mixed emotions at the time of discharge and during the following months. Despite acknowledging that they were prepared for discharge, some parents indicated that they would like a broader preparation, incorporating the multiple roles, responsibilities and adaptations that are required when taking an infant home from NICU. This knowledge could be useful to help inform service development and intervention (promotion and

prevention) at the discharge stage. Given the literature that exists demonstrating the negative impact of NICU admission on parents' emotional wellbeing (Davis et al., 2003) and the development of the attachment relationship (Fegran et al., 2008) it is highly important to provide parents with appropriate support. Further consideration of how information is provided prior to discharge, how to increase community-based professionals knowledge of the support needs of these families and the introduction of greater parent-to-parent support should be encouraged.

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CHAPTER 2: MAJOR RESEARCH PROJECT

An exploration of parents' experiences of having an infant who requires surgery using Interpretative Phenomenological Analysis.

Ruth A. Hind

Mental Health and Wellbeing

University of Glasgow

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow

G12 0XH

Prepared in accordance with guidelines for submissions to The Journal of Reproductive and Infant Psychology (Appendix 1).

Plain English Summary

Background

In Scotland there are around 58,000 births every year. Of these infants approximately 11% will need extra care when they are born, which might include surgery. There is a lot of research that describes the experiences of parents who have an infant in the Neonatal Intensive Care Unit (NICU), but less is known about parents' experiences of infant surgery and how they cope with this.

Project Questions

This project aimed to explore the experiences of parents who have an infant that needed surgery soon after birth.

The project aimed to look at:

- What are the challenges faced by parents of infants needing surgery?
- How do parents experience their infant being transferred from one hospital to another?
- How do parents cope with having an infant who needs surgery?

Method

Participants

Inclusion Criteria

- Parents of infants who have had surgery soon after birth
- Parents of single birth infants

Exclusion Criteria

- Parents of infants who are not likely to survive
- Parents of infants who need heart surgery
- Young parents less than 18 years of age
- Parents who do not speak English as their first language

Recruitment

Staff at the surgical NICU identified parents by reviewing the admissions register for the Unit. A member of staff (not the main researcher) provided parents with written information about the study while their infant was in the unit.

Consent

Parents were provided with written information about the study to help them decide whether they wanted to take part in the research. If they decided to take part, the researcher contacted them to arrange an appointment to answer any questions they had about the research, to gain their written consent and to complete the research interview.

Design

In-depth interviews lasting between 60 and 80 minutes were conducted with five parents. Interviews were recorded using a digital voice recorder. The recordings were typed up word for word and this data was analysed using Interpretative Phenomenological Analysis (IPA) to identify common themes in the interviews. IPA was used because it aims to explore in detail a participant's experience, their understanding of it and the meaning they give to situations they experience¹.

Main findings

Having an infant who needs surgery is a stressful experience for parents. The main themes that the study identified were: the intense emotional and psychological impact of being told about their infant's diagnosis and need for surgery; the difficulties associated with having a baby in the NICU and how this affected their role as a parent; how they coped with the experience overall and how it has affected their thinking about their and their infant's future.

Conclusions

The results of this study have implications for clinicians, policy makers and service managers who are involved in the delivery and design of services that care for infants who require surgery and their families. Having a better understanding of parents' experiences may help clinicians and services to improve the service they provide to these families.

¹ Smith, J. A., and Osborn, M. (2008) Interpretative Phenomenological Analysis. In Smith, J. A., (Eds.) *Qualitative Psychology. A Practical Guide to Research Methods*. Second Edition. (Chapter 4). London: Sage Publications.

Abstract

Background

Each year approximately 11% of infants who are born will require extra care, which often results in admission to a Neonatal Intensive Care Unit (NICU). For some of these infants extra care will include surgery. Research to date has focused on the experiences of parents of infants in the NICU, with less known about parents' experiences of infant surgery. NICU admission is often characterised as a time of significant stress and distress for parents. For parents of surgical infants there may be additional stressors, including the required transfer between the maternity and children's hospitals for surgery. The management of transfers between hospitals for this vulnerable population is increasingly topical in view of the establishment of the neonatal managed clinical networks in the United Kingdom, which will result in increased movement of infants between hospitals providing neonatal care at different levels.

Aims

To explore the experiences of parents who have an infant that requires surgery and transfer between hospitals. To explore how parents cope with this experience.

Methods

This qualitative study was conducted and analysed using Interpretative Phenomenological Analysis (IPA) approach. Purposive sampling was used to recruit a relatively homogenous sample. Semi-structured interviews were conducted with five parents.

Results

The results of this study suggest that the experience of having an infant who requires surgery is particularly challenging for parents. Five superordinate themes were identified that represented parents' experiences: being told – the psychological impact of diagnosis; living on the ward; becoming a parent to a critically ill baby; coping and facing the future.

Conclusions

The findings of this study have implications for clinicians, policy makers and service managers who are involved in the delivery and design of services that care for infants who require surgery and their families. In light of the limited research that has been conducted

in this area, suggestions are made for future research that will enhance service provision for these families.

Introduction

The birth of an infant is a significant life event, which has a profound impact on a family who must adapt to their new arrival. The addition of an infant requires parents to transition to a new role and adapt relationships with family, friends, their social and working lives. Nyström and Öhrling's (2004) literature review (n=33 studies) into the parenthood experiences of mothers and fathers during their child's first year described this period as 'living in a new and overwhelming world' (p.324). In the year ending March 2012, there were 57,911 live and stillbirths in Scotland (ISD, 2013). Of the total live infants born in Scotland annually 11.4% require additional care in a Neonatal Intensive Care Unit (NICU), High Dependency Unit (HDU) or Special Care Baby Unit (SCBU) (ISD, 2013). Infants require extra care for various reasons, including prematurity (born before 37 weeks gestation; WHO, 2013), poor intrauterine growth or congenital diseases. This extra care may include surgery (gastrointestinal, renal, cardiac, orthopaedic, or neurosurgery).

There is a wealth of literature reporting parents' experiences of having an infant in a NICU, which all infants who have surgery will require. Parents experience high levels of distress, anxiety, depression and a sense of loss and grief when their infant is in NICU (Cleveland, 2008; Obeidat, Bond & Callister, 2009). Parents also reportedly fluctuate between feelings of inclusion and exclusion from their infant's care (Cleveland, 2008; Obeidat et al., 2009). Premature birth and immaturity of the infant can affect parental experience, attitudes and behaviour, and consequently may affect the parent-infant relationship and the child's outcomes (Muller-Nix et al., 2004). Mothers of high risk infants and those who experienced traumatic stress in the perinatal period have been found to be less sensitive and more controlling towards their infants at six months than mothers of healthy infants (Muller-Nix et al., 2004). Furthermore, high anxiety in mothers of very low birth weight infants in NICU has been found to adversely impact cognitive development and lead to increased incidence of internalising behaviours (emotionally reactive, anxious/depressed, somatic and sleep problems) at two years of age (Zelkowitz, Papageorgiou, Bardin, & Wang, 2009). These findings indicate the long-term impact that having a hospitalised infant can have on the parent-infant relationship and infant development. The main sources of stress for parents in the NICU include the impact that infant illness has on the parental role, infant appearance and behaviour (Miles, 1991). Within literature about parental experiences, fathers have generally been included to a lesser degree (Carter, Mulder, Bartram, & Darlow, 2005; Fegran et al., 2008). Some

research suggests that fathers experience NICU differently to mothers; with mothers feeling that they have greater responsibility and control of their infant's care and a need to be confirmed as a mother, whereas fathers describe confidence in letting staff care for their infant (Jackson, Ternstedt & Schollin, 2003) and that they strive to find a balance between family life and work (Pohlman, 2005).

The experience of parents who have an infant that requires surgery is less well researched (Diffin, Shields, Cruise & Johnston, 2013; Harvey, Kovalesky, Woods & Loan, 2013). The Diffin et al. (2013) review had four main areas of focus: parental stress and psychological distress in the NICU; parental experience following discharge; and finally, parenting an infant who required surgery. The first three areas of the review used studies with mixed samples of surgical and non-surgical infants, whereas the latter included four quantitative studies with surgical samples (Chen et al., 2007; Doherty et al., 2009; Farooqui et al., 2006; Joseph, Mackley, Davis, Spear & Locke, 2007). Parents of surgical infants were reported to have elevated levels of stress in the initial months following birth (Doherty et al., 2009), which continued to adversely impact parental wellbeing in subsequent years, particularly in families whose infant continued to have clinical problems in later childhood (Chen et al., 2007). Surgical infants have longer-term complex health and developmental needs than non-surgical infants and exposure to invasive procedures that may lead to their parents being at increased risk of stress (Diffin et al., 2013). Two studies in the Diffin et al. (2013) review explored the experiences of fathers (Farooqui et al., 2006; Joseph et al., 2007). They reported that the altered parental role and poor communication with healthcare professionals were associated with the highest levels of stress. For mothers the NICU environment, appearance of the baby (Farooqui et al., 2006) and poor understanding of the diagnosis (Doherty et al., 2009) were associated with elevated levels of stress. Doherty et al., (2009) found that knowledge, appraisal based coping and cohesive family functioning were most predictive of parental mental health.

Parents' experiences of having a child who requires cardiac surgery has been studied more extensively than other conditions, however, the samples usually include children from a wide range of age groups (Diffin et al., 2011). Harvey et al. (2013) explored the experiences of mothers of infants undergoing complex heart surgery for congenital heart disease (CHD) by analysing retrospectively written journal entries for the time periods: before, during and after infant surgery. The study identified six themes: feeling intense

fluctuating emotion; navigating the medical world; dealing with the unknown; facing the possibility of their baby dying and finding meaning and spiritual connection with the 'umbrella' theme of 'mothering through it all' (Harvey et al., 2013). A strength of this study is that the identified themes were validated by mothers who had had a similar experience. Rempel and Harrison (2007) explored mothers' and fathers' experiences of parenting an infant with CHD, by interviewing parents of children (n=9) aged between two months to five years of age. The children had undergone one (n=1), two (n=4) or three (n=4) surgeries. Rempel and Harrison (2007) identified that parents took steps to ensure the survival of their infant, themselves as individuals and their couple relationship. To ensure the survival of their infant, parents participated in infant care and learned complex monitoring and treatment administration skills to ensure their infants gained weight and were protected from infection. Parents utilised a range of coping strategies to manage the worry associated with having an infant with CHD. Strategies included: directing their mind away from thoughts about their infant's mortality; trying to view their child as normal; developing trust in medical staff and/or God and accepting what was out of their hands. Parents also spoke about the importance of 'being on the same page' as one another when organising and negotiating infant care (Rempel & Harrison, 2007).

Given that parents of NICU and surgical infants are at increased risk of stress, depression and anxiety than parents of healthy infants it is important to consider their coping and resilience. Lazarus and Folkman (1984) defined coping as the cognitive and behavioural approaches that people use to manage the internal and external demands of situations that are appraised as stressful (p.141). Rempel and Harrison (2007) identified a number of coping strategies that parents of infants with CHD used, as discussed above. Harvey et al. (2013) identified similar coping strategies in their sample of mothers who aimed to: find inner strength to provide their infant with love and strength; advocate for their infant; accept the uncertainty about why a child develops CHD and that finding meaning is something that may not be possible until a later time; and seek faith, spirituality, the support of family, friends and other parents with the same experience. Doherty et al. (2009) found that mothers and fathers of surgical infants generally utilised similar coping techniques, most commonly they would positively reinterpret the situation, attempt to accept their infant's condition (CHD) and identify solutions for any difficulties encountered. However, some differences were evident in mothers and fathers coping strategies. Mothers were significantly more likely to express their distress, seek social,

spiritual and religious supports, whereas fathers were significantly more likely than mothers to use alcohol to help them cope (Doherty et al., 2009).

As described above, there is currently limited literature available regarding the experiences of parents of surgical infants, yet the value that research in this area could have in improving healthcare outcomes for the whole family has been emphasised (Diffin et al., 2013; Harvey et al., 2013). Diffin et al. (2013) identified a lack of research on parental coping and research that is not solely focused on the experience of parents of preterm and low birth weight infants. Of the research conducted with parents of surgical infants most have utilised quantitative methodologies (E.g. Doherty et al., 2009; Farooqui et al., 2006; Joseph et al., 2007) and the qualitative studies that have been conducted have some methodological limitations. For example, Harvey et al. (2013) used a retrospective design and the sample did not include fathers. While, Rempel and Harrison's (2007) sample included children of different ages (from two months up to five years) who were at different stages of complex treatment. Furthermore, both studies focused solely on parents of infants with CHD.

For families who have an infant that requires surgery there is a difficult trajectory of long hospital admissions, operations, stressful and traumatic experiences - some of which may have adverse long-term outcomes including poorer developmental or health outcomes and even death. Exploring the experiences of parents during this critical time, as they adapt and adjust to becoming parents to a medically fragile infant will improve our understanding of their needs and how professionals can best support them.

Research Aims

This project aimed to:

1. Explore the challenges faced by parents of infants requiring surgery, including the experience of transfer to another hospital.
2. Explore how parents coped with the experience of having an infant who requires surgery.

Methodology

Design

This qualitative project utilised Interpretative Phenomenological Analysis (IPA), to explore in detail a participant's experience, their understanding of it and the meaning they give to their experiences (Smith & Osborn, 2008). IPA has previously been used in studies that explore parents' experiences of their children's ill health, including childhood onset of anorexia nervosa (Cottee-Lane et al., 2004) and adolescent onset of chronic pain (Jordan et al., 2007).

Sample

Participants were parents of infants who attended the Royal Hospital for Sick Children (RHSC), Yorkhill, for surgical interventions and had been cared for in the surgical NICU, hereafter referred to as NICU. The inclusion and exclusion criteria were designed to ensure the sample was relatively homogenous and to reduce potential harm or distress to participants.

Inclusion Criteria

- Parents of infants who required surgical intervention within the first twelve months following birth.
- Parents of single birth infants.
- Parents of infants who were considered likely to survive by medical staff.
- Parents of infants whose surgery was five or more days ago.

Exclusion Criteria

- Parents of infants who required cardiac surgery.
- Parents less than 18 years of age.
- Parents who did not speak English as their first language.

Procedure

A member of the direct care team with access to infant medical records as part of normal practice identified potential participants. Potential participants were given the participant information leaflet (Appendix 4) and response form (Appendix 5). If parents were interested in participating they were asked to return the response form. Interested parents

were contacted by the researcher to provide any additional information and arrange an appointment to complete the interview. Prior to completing the interview, parents provided written informed consent (Appendix 6) and agreed to the infant's ward being notified of their participation (Appendix 7).

Semi-structured interviews (Appendix 8, Interview Schedule) lasting between 60-80 minutes were conducted in a private room in the hospital where the infant was receiving care. The interviews were recorded using a digital voice recorder. When a mother and father dyad participated they were interviewed separately to allow them to express their personal experience. Interviews were completed flexibly; using prompts and probes to fully explore the parent's experience. As the project involved interviewing families who had recently experienced a significant life event the researcher remained sensitive to this and care was taken to build rapport before beginning the interview. If any concerns about a parent's emotional or psychological wellbeing were identified during the interview an appointment with the ward Clinical Psychologist could be made. Interviews were concluded with a review of their interview experience, current emotional state and an informal conversation. Participants were also provided with a list of available supports (Appendix 9).

When to approach parents was considered carefully; a minimum of five days following their infant's surgery was considered appropriate, as this is when families would routinely be offered a Clinical Psychology appointment as part of standard care. Of the limited research conducted with parents' of surgical infants some have involved data collection within the first few months following the infant's birth, however, this research has mostly employed quantitative (e.g. Doherty et al., 2009) rather than qualitative methodologies (e.g. Rempel & Harrison, 2007). Some qualitative studies about parental experiences in NICU have recruited parents while their infant remains an inpatient (Hollywood & Hollywood, 2011; Heermann, Wilson & Wilhelm, 2005), which demonstrates parents are willing to participate in research at this time.

Data Analysis

Interviews were transcribed verbatim and all potential identifiers of person or place were anonymised. Transcripts were checked for accuracy by the researcher. The transcripts were analysed using IPA protocols following the recommended procedures (Smith & Osborn,

2008). Data analysis involved the researcher familiarising themselves with the transcripts to identify themes that reflected the parent's experience. One transcript was coded independently and discussed with supervising researchers; this process confirmed the themes identified by the researcher. Smith, Flowers & Larkin (2009) suggest this process can demonstrate commitment to producing research with improved validity.

Researcher Reflexivity

In IPA, the aim is to develop an understanding of the participant's perspective of a particular phenomenon, however, the role that the researcher's experiences and beliefs have upon interpretation is acknowledged (Smith, Flowers & Larkin, 2009, p.34-37). Therefore, care was taken to acknowledge the researcher's experiences and beliefs that might influence their conduct in the interviews and their interpretation of parental experiences. As a Trainee Clinical Psychologist, the analysis was noted to be influenced by models of mental health, coping, loss, adjustment and child development (including attachment). Furthermore, the researcher had worked clinically with parents of infants who require intensive care; which provided the researcher with insight into parental responses and some of the challenges associated with having a critically ill infant. It is possible that the results would be analysed differently under alternative theoretical influences.

Ethical Approval

The study was approved by the University of Glasgow, West of Scotland Research Ethics Committee (Appendix 10) and NHS Greater Glasgow & Clyde Research & Development (Appendix 11).

Results

Participants

Sixteen families were identified as suitable to include in the research. Of the 16 families approached, six parents responded to the invitation to participate, one of which was not contactable. A total of five parents participated. The sample size attained for this research is in accordance with the guidance provided by Smith, Flowers & Larkin (2009, p.51-52), who suggest a sample size of between four and ten interviews is typical for qualitative

research conducted as part of a professional doctorate. Participant information is provided in Table 1.

Table 1. Parent and infant demographic details

Parents	
Relationship to infant	Mother=4 Father=1
Age (Years) –Median (Range)	24 (19-39)
First pregnancy	Yes=3 No=2
Diagnosis received and told about surgical need during the antenatal (A) or postnatal (P) period?	A=4 P=1
Infants	
Sex	Male=4*
Gestational age (weeks + days) - Median (Range)	35 (25+1 – 36+1)
Birth weight (grams) - Median (Range)	2340 (910-2500)
Reason for surgery**	Diaphragmatic hernia=1 Gastroschisis=2 Gastro-oesophageal reflux disease=1 Inguinal hernia bilateral=1 Retinopathy of prematurity=1
Number of surgeries completed	One surgery=1 Two surgeries=3
Time since last surgery at time of interview (days) - Median (Range)	15 (10-26)

Note: *Two parents of one infant participated. ** Two infants had multiple surgeries.

Five superordinate themes were identified concerning the experiences of parents who had an infant that required surgery, including: being told – psychological impact of diagnosis; living on the ward; becoming a parent to a critically ill baby; coping and facing the future (Table 2).

Quotations from interviews have been selected to illustrate each theme. Quotations will be presented in italics, with the researcher’s comments in bold and pauses indicated by ellipsis. Square brackets will be used when text is removed or inserted to improve relevance, anonymity or clarity of the quotation. Due to one father and four mothers participating, care has been taken to provide anonymity for him in the quotations.

Table 2. Superordinate and emergent themes relating to parents’ experiences of having an infant who requires surgery.

Superordinate themes	Emergent themes
Being told – Psychological impact of diagnosis	Emotional impact Causal attributions Threat to infant Lack of certainty and control
Living on the ward	Overwhelming impact of the ward environment Staff Caring attitudes and ‘special treatment’ Communication
Becoming a parent to a critically ill baby	Meeting baby Separation Becoming involved
Coping	Problem focused Emotion focused
Facing the future	Thinking about discharge Hopes for a ‘normal’ future

Being told – psychological impact of diagnosis

Emotional impact of diagnosis

Parents were informed that their infant would require surgery at different times; four parents found out during antenatal screening appointments and one parent found out post-natally that their infant required surgery due to complications arising from prematurity. All parents’ emotional responses to being told about their infant’s requirement for surgery

were relatively similar. When parents were informed about their infant's need for surgery they experienced strong emotional responses, including: anxiety, fear, anger, shock, disbelief, sadness, and grief. Parents continued to experience changeable and intense emotions during their infant's surgery, NICU admission and during their recovery at the time of interview. The following quotation demonstrates one parent's shock and emotional struggle after being told their infant would require surgery and that their condition could be life-threatening:

“The nurses showed us around the NICU and it was just, it was so unreal, we were just like ‘Is this really happening, is this really?’ And basically after the MRI [Magnetic Resonance Imaging scan] they said ‘He’s got quite slim chances he doesn’t, just so you know, it looks really severe’ so we were just like completely in shock.” (Participant 3)

Parents spoke directly and indirectly about a sense of loss and grief following their infant's diagnosis. The losses that parents experienced as a result of their infant's health condition were multiple, including the loss of a normal or expected pregnancy, delivery and initial meeting with their infant. The following quotation demonstrates a parent's sadness and grief about their infant's diagnosis:

“I needed time, I needed to be able to still kind of be able to, kind of, to [sighs] not grieve, but you know, to be upset about the fact that my baby has to go through this.” (Participant 2)

Causal attributions

While experiencing disbelief and shock about their infant's need for surgery parents questioned and sought to understand why this had happened to them and their infant. In most cases parents were not given an explanation by medical staff as they were told the aetiology of their infant's difficulties were unknown. Three parents discussed their attempts to make causal attributions about why their infant needed surgery, with two of these parents' comments reflecting a sense of guilt and self-blame:

“I think a sense in me that ‘Oh, have I done something in my life that’s caused this?’ You know, somewhere in my past have I made a poor decision, have I eaten

something that's made me sick and caused this to, [gentle laugh] I don't, you know, affected the chromosomes in my baby or something.” (Participant 4)

Threat to infant

Following diagnosis, parents were concerned that their infant's condition and the surgery they required posed a threat to their infant's health and potentially their life. The threat to the infant was manifest in a number of ways, including the requirement for more frequent antenatal care, planned early delivery - for those who knew antenatally - and for all parents the knowledge that their infant would require NICU admission:

*“So I knew...from them just suggesting that I would have to be there a lot, that it was, you know, quite high risk. **Ok.** So that's what I worried about, I worried about him dying.” (Participant 2)*

Conversations with medical and surgical staff provided parents with information about the level of threat their infant's condition posed; receiving this information was sometimes overwhelming as it required the parent to directly face the life-threatening nature of their infant's condition. In the following quotation the parent describes their response to being informed about the seriousness of their infant's prognosis, which made it difficult for them to maintain optimism and hope:

*“They didn't want to give you too much hope, they wanted you to, kind of, be realistic about it [...] they said ‘Look we don't get babies any sicker than this, this is about as difficult as they come’ you know. **Ok.** I was like ‘Christ’ it was really hard to hear this stuff. **Mhm.** You know, because I wanted some hope, just little nuggets of something, but they weren't really giving it to us.” (Participant 4)*

Lack of certainty and control

Lack of certainty and control were frequently reported by the parents throughout their experience. For all parents, the diagnosis of their infant's condition and subsequent need for surgery was unexpected. To manage this uncertainty they sought to develop medical understanding and knowledge. However, even with this new knowledge the outcome of

surgery and any potential longer-term impact of their infant's condition, for example developmental delays, remained uncertain and out of their control:

“There’s not that many times in my life, that I’ve had like a thousand per cent not knowing what’s going to happen, [...] just completely not knowing and having to completely surrender.” (Participant 3)

Living on the ward

Overwhelming impact of the ward environment

Adjusting to an unfamiliar medical environment was identified as a theme in all parents' interviews. They often found the ward environment stressful due to the unfamiliar medical terminology and equipment that monitored or supported their infant's life:

“You expect him to have tubes and monitors on but you just don’t expect them to make all the noises they make, the beeps an’ [all] that, they’re quite scary all the time.” (Participant 1)

One parent spoke about how seeing their infant critically unwell and dependent on machinery was particularly challenging:

“I saw him [...] on this very rapid ventilation and he just looked like he was like a machine, he didn’t really seem like there was any life in him at that point, and it was really, really hard.” (Participant 4)

This parent struggled to observe their critically ill infant whose breathing and life were being artificially maintained, which may have impacted on their ability to further develop their relationship with their infant. This parent also spoke about their infant subsequently requiring a more invasive type of life support, the intensity of which led to them feeling disbelief, shock and that the situation was surreal.

The following quotation demonstrates parents' experience of the NICU as an overwhelming environment. Parents experienced the ward as removed from 'normal' life and an emotionally challenging place to be even if their infant was physically stable and

recovering. Despite parents reporting that they adjusted to the NICU environment with time and as their infant's health improved, the ward remained a stressful place:

“You're just in this bubble where everyone is like going through something intense and if they're not going through it they're managing it [...] there's sirens and alarms going off in the background and there's the smell of the antiseptic, so even if you're not fully in an intense situation, there's babies crying in the next bed or something, there's something that can be stress inducing.” (Participant 3)

The analogy of being in a bubble indicates that this parent experienced the ward environment as surreal and detached from everyday life. Parents' awareness of the other infants and families in the ward could often add to their stress - particularly when other infants were acutely ill.

Staff

Parents reported overwhelmingly that they appreciated and valued the care provided by medical, surgical and nursing staff; yet all parents spoke about their need to get to know the ward environment, routines and staff:

“For me it's also a bit difficult being in a space that's running a bit like the army, it's, it feels a bit like being in the war here, you have a rank system, they're looking after your child but they're also just doing their job.” (Participant 4)

This parent uses a war analogy to describe their experience of being in the NICU, where parents need to abide by the ward routines and rules, endure a challenging and stressful environment, including pain, ill health and facing the possibility of their infant's death. This parent also made reference to their perception that there was a rank system on the ward and that parents lacked any power or control in this environment. The parent also differentiated the role of professionals and parents, by indicating that their motivations and attitudes towards caring for their infant may be somewhat different.

Another parent spoke about the difficulties associated with frequent staff changes on the ward:

“Somebody came in an’ took one of [baby’s] records an’ I went [sharp intake of breath], ‘There’s a man just came here with a purple shirt on an’ he’s just took his records away out, what does that mean?’ [...] I thought he’s a surgeon or something, he’s coming tae take him to theatre [laughs] but it was just to check what medication he was on.” (Participant 1)

The above quotation illustrates this parent’s uncertainty about staff roles in the ward and their persistent anxiety about their infant’s health and potential need for further surgery.

Caring attitudes and ‘special treatment’

All parents reported experiences of finding healthcare professionals helpful and containing, both during the antenatal and postnatal periods. All parents who met their infant’s surgeon had a positive opinion of them and this increased the parents’ confidence when their infant went for surgery. Interestingly parents spoke about the caring and personable attributes of the surgeons almost as much as their surgical proficiency, demonstrating the importance of interpersonal and communication skills in mediating parents’ trust and confidence. The following quotation describes one parent’s experience:

“The surgeon explaining, it was just so clear and so precise [...] he just sat there and he said you know, ‘We’ll just wait here until you have no more questions’. And then after we had no more questions, he just sat there for a little bit and just said, ‘We’ll just give you a minute’ and it was just like, so at no time did it feel rushed, or... which really helped, it just felt like they really cared.” (Participant 3)

Parents spoke about their perception that they were given extra or special treatment by medical and nursing staff because of the situation they were in. The following parent spoke about the gratitude and warmth they felt when a nurse provided them with food during a stressful time:

“They brought me into this room [...] while they were stabilising [son], and again I was like, ‘Is he gonna be ok?’ And um, what I remember is one of the nurses made me some toast, I hadn’t eaten all day, my stomach was like empty [laughed] acidic and horrible feeling. And that was really sweet, that made me feel really good.” (Participant 4)

Communication

Parents also experienced situations when communication with health care professionals was counterproductive. In particular, parents found it anxiety provoking when there were inconsistencies in the information they received or when information was not shared with all staff. The following quotation refers to the communication of accurate information but not in timely or appropriate manner, the communication was from the children's hospital to a parent in the postnatal ward:

“They had to phone me- for my permission, like obviously [be]fore he went to surgery, ...an' they phoned me, an' they told me that [...] he was going to theatre an everything, an' they says that they had to put his stomach back in AND his bowel, an' I was shouting at the woman on the phone I says, 'you've lost ma baby, that's no ma baby, ma baby's eh- stomachs' not out it's just his bowel', [...] an' they kept telling me that it was out an' I was going off ma head at them on the phone, I says 'no you've got the wrong baby over there, that's no ma son.’”
(Participant 1)

The following quotation demonstrates the adverse impact that the use of medical terminology can have when communicating with parents who do not have a shared medical knowledge or language:

“The doctor [...] used the word morbidity like three times, at the time I thought that meant death, so at the time she said 'it has a high morbidity rate' which basically means long hospital stays with lots of complications and all that, but I thought, two or three weeks later to look it up, did she really say like three times in that conversation that there was a high death rate?” (Participant 3)

Becoming a parent to a critically ill baby

Parents spoke about how the experience of having an infant that required surgery impacted on the development of the parental role and the parent-infant relationship. Parents frequently spoke about how their infant's health condition influenced their fulfilment of typical experiences that parents expect to have when they have a baby.

Meeting baby

All parents reflected on the first time that they met or saw their infant and how this differed from their expectations. Parents did not have the opportunity to hold, be close to or spend much time with their infant after birth. In most cases infants were prepared within hours of birth for transfer from the maternity hospital to the children's hospital where they would have surgery. Parents recognised that their experience was not 'normal' and didn't feel the satisfaction or pleasure that they had expected:

"Horrible, it wasn't even like the happy feeling that you should have when you have a baby but like, 'God, what's happening?' Mhm. But, it was just all these machines and he had a big tube down his throat and it was just horrible."

(Participant 5)

One parent spoke about the direct impact that their uncertainty about their infant's survival had upon their feelings of attachment when they met them for the first time:

"I went over and they said, 'Do you want to see him?' And I just kind of put my hand on his head and said, 'OK thanks', and I walked away. And I think...I was kind of not sure that he was going to make it at that point, you know, and I didn't really want to... [...] I didn't want to get too attached. [...] And it was kind of a weird way to see a child of yours, you know that, usually you're like, 'Oh wow, there's my little baby' but there was a sense of I'm not sure of what's going on here yet, you know, and that was very difficult. I realised afterwards that I was, you know, I was like very cold about it." (Participant 4)

In the above quotation the parent acknowledged their fear about becoming attached to or developing a relationship with their infant. Through keeping their distance emotionally and physically they attempted to protect themselves from future pain and grief, if – as they feared – their infant died. The parent compared their experience to 'normal' parents' experiences of meeting their infant and how theirs differed from it. Parental perceptions that they were 'missing out' on normal experiences led to feelings of sadness, loss and disappointment.

Separation

All mothers struggled with the separation from their infants, particularly in the immediate postnatal period. The following quotation is from a mother who was unable to be close to their infant due to her own physical ill health following delivery and admission to a postnatal ward:

“You’re so used to having them, like, an’ you feel them every day moving about inside ye [...], an’ then you have them and then like you expect to be with them an’ you just cannae be whatsoever, like you’ve nae option to be with them.”

(Participant 1)

The mother conveys her desire to be with her infant and that she missed the connection that had developed during pregnancy with them. Three of the mothers in the sample were admitted to the postnatal ward while their infant was transferred to the children’s hospital. The mothers found this particularly challenging as they all shared a room with other mothers who had their babies with them. Drawing social comparisons to the other mothers led to them feeling different and accentuated that they were missing out on typical early experiences with their infant.

“I signed myself out [laughed] [...] I says ‘I need to leave I cannae stay in here any longer’ [...] everybody had their baby to like watch an’ I just said ‘I cannae sit in here any longer I cannae sit an’ do nothing’ [...] It was just a bit hard wi[th] everyone else having their baby and you’re thinking aw I feel a bit helpless ‘cause you cannae do nothing.” (Participant 1)

Seeing other mothers caring for their infants, receiving gifts and introducing their baby to their families was very difficult for the mothers who did not have their baby with them on the postnatal ward. All of these mothers subsequently sought early discharge to be with their infant. Mothers found the photos of their infant provided by the maternity hospital somewhat comforting, however, parents emphasised the importance of proximity to their infant to help them feel reassured about their care and condition. The following quotation demonstrates a parent’s motivation for being near their infant when they were critically ill:

*“When he was first born [...] you didn’t know what was going to happen, it was sort of like critical, I hated leaving. **What was it about leaving that was difficult?** Just ‘cause you were going home, and when I was here you knew everything and you seen how he was.” (Participant 5)*

The mothers and father in the study reported that the mother being in a different hospital to their infant left fathers in a difficult position where they had to divide their time between their partner and infant. The physical transfer of the infant was only experienced as stressful by the father, who perceived the journey as anxiety provoking despite his confidence in the medical staff and equipment involved. Thus the main concern about the infant’s transfer to the children’s hospital was centred about the separation from the mothers and the challenges that ensued for fathers who had to divide their time between two hospitals.

Becoming involved

Seeking proximity and becoming involved in infant care led to parents feeling that they had a more defined role as parents and began to regain some control. As the infants were recovering there was a reduction in wires, monitors and medical equipment required making it easier for parents to become more involved:

“At first you weren’t really allowed to do anything and it was always the nurses that were with him and stuff, but [...] now he’s out of his incubator, he’s in a wee cot, I can take him out whenever I want.” (Participant 5)

Coping

Parents were asked about what had helped them to manage throughout their experience from diagnosis to the time of the interview. Diverse strategies were utilised by parents at different times during their experience.

Problem-focused

All parents spoke about the uncertainty associated with their infant requiring surgery and sought information to improve their understanding, which alleviated some of their distress. The following quotation describes a parent’s attendance at an antenatal appointment:

“I used tae go in with a notepad every day like this, ‘Look [laughs], I’ve got these questions’ [...] ‘cause I, you used to think of questions like when you come out and you’d be, ‘Aww I wish I had asked that,’ [...] you feel a bit better when you knew [...] exactly what was happening.” (Participant 1)

Parents wanted to know the facts and have accurate information about what their infant’s surgery would involve, the potential complications and future prognosis. This was also true for all parents seeking updates on their infant’s condition throughout their NICU admission. Gathering information from professionals and other sources was an active coping strategy utilised by parents to reduce the uncertainty of the situation. When parents had a clearer idea of what they were facing they were in a better position to prepare and equip themselves, both emotionally and practically.

One parent spoke about how, with their partner, they found a way to manage the walk from their accommodation to the NICU while recovering from a caesarean section. The parent shared this learning with other parents:

“We just kept asking people, and we asked this doctor and she said, ‘Well if you go through A&E there’s wheelchairs in there,’ and we went and asked again in A&E and they said take it [...] that was like key, ‘cause then we like, weeks later I would see mothers doing the hobble in, and I was like ‘You know you can use the wheelchairs in A&E’ and they were like ‘oh thank God!’” (Participant 3)

All parents spoke about the positive social support they gained from their families. This support included practical support, such as help to prepare for the infant coming home, looking after other children, and the provision of emotional support, when required. One parent spoke about receiving support from their mother and how this enabled more time with their infant:

*“She’s leaving in a few days, and I don’t know what I’m going to do, it’s going to be horrible. **Uhuh.** Obviously because my mum isn’t here, but also because she was doing all the cooking and cleaning and I can’t even fathom making my dinners from now on. [...] I’m spending so much time in the hospital [...] I go back home*

for dinner and I just ... I can't even think, I have to have somebody else put ... a plate in front of me because it's so emotional ... it's draining being in here."
(Participant 2)

Emotion-focused

All parents discussed their strong emotional response to their situation and that they found ways to moderate their distress. One parent described their realisation that they had to find ways to manage their emotions:

*"My mood and my sanity, how I felt, was completely related to how he was doing, **mhm** so if he was having a good day I was having a good day [...] I was completely dependent on this outside circumstance for my happiness or for my peace."* (Participant 3)

Parents also spoke about the requirement for them to become more accepting of things that they could not change and develop trust and patience to manage the difficult situation they were in.

"I'd say I came to terms with it after the two weeks [after diagnosis]. What can you do? I just accepted it and had to stay positive. I feel like if I was going to stay negative, if I was going to be really negative about it and sad and upset that that would just, [sighs] that wouldn't be good for him, you know. There's so much to say that if the mother's stressed that it really affects the baby." (Participant 2)

Some parents described coping through denial or becoming detached at times, for example, the parent (Participant 4) who earlier described meeting their infant and not fully engaging with the situation or attempting to develop their bond with their son. The parent later reflected that they had done this to protect themselves from future pain if their infant died. Another parent chose to be alone when their infant had surgery as they did not want to be around other people who - they feared - would want to focus on and talk about the surgery. Another parent spoke about how they would try to find a positive in challenging situations, which sometimes required them to be somewhat detached from the reality of the situation. The following quotation refers to a parent's response to seeing their baby when they were critically ill on a heart and lung bypass machine:

“I thought, ‘Oh God, he’s on a bypass it’s going to be crazy,’ but he was just actually, completely sedated, but he just looked peaceful to me [...] Yeah, just sort of grasp onto what’s gonna, just [give a] feeling of relief somehow, I just wanted to, cause it’s not, I mean obviously I spent a lot of time worrying but it didn’t help him, it didn’t help me. So I would look for reasons to feel better, I guess.”

(Participant 3)

Parents frequently reframed or reappraised their situation, directing their focus to positive aspects of their situation. Some parents discussed their thoughts about surgery; all acknowledged that there was anxiety and stress associated with their infant requiring surgery, but there was also recognition by three parents that surgery was necessary and desired as it would promote the infant’s health and survival. One parent who found the NICU emotionally exhausting positively reappraised their infant’s long admission, making it easier for them to cope with the remainder of the admission:

“When the nurses are doing their cares for him, I’m just picking up tips and I’m like ‘Oh, that’s a good idea,’ so I feel like for a first-time mum it’s actually quite beneficial ... in a weird way to have this time, where, um...I don’t have him home, where I’d like him to be, but I’m able to kind of ease into my role as a mother.”

(Participant 2)

Another parent spoke about making social comparisons to other parents who they perceived as less fortunate:

“You just had to be thankful that he was still here, other people have it worse.”

(Participant 5)

One parent spoke about how their infant’s condition required them to attend additional antenatal appointments. During one of these appointments a serious pregnancy complication was identified, which necessitated an emergency caesarean section to prevent this mother from becoming ill and potentially dying:

“If he didnae need surgery then would the two of us even be here? [...] I suppose everything’s just happened as it should have happened.” (Participant 1)

The following quotation is from a parent whose infant had been in hospital for approximately six months at the time of interview. The parent looked back over what was a very protracted and emotionally challenging experience and concluded that in addition to their infant surviving, there had been gains from their experience, in terms of self-growth and appreciation for what is important and valuable in life:

*“Looking at the whole journey, it’s been amazing. [...] we see things differently now, and I think we’re all kind of, we appreciate things more [...] we were in a sense a bit asleep before [...] I think we were in this space of just kind of goes, ‘Oh having a baby, la de dah, de dah’ you know, and not really appreciating how special that is [...] I’ve definitely felt like I’ve been alive the last five months I haven’t been sleeping, I’ve been alive. **Uhuh.** And in a way that has felt good.”* (Participant 4)

Self-care and the ability to express their thoughts and feelings were also helpful; however, both were sometimes difficult to do. For example, a barrier to self-care was that parents often found it difficult to spend time away from the ward; while a barrier to self-expression was that sometimes friends or family would try to problem solve, rather than encourage emotional expression. One parent did not find speaking to others about their anxieties helpful. Three parents found speaking to parents of other surgical infants particularly helpful as they believed that they truly understood their perspective and concerns. However, opportunities to engage with other parents were limited due to the absence of a formalised group or a communal space in the ward for parents:

“The expressing room is the only room on this ward that is not [...] a hospital room. [...] That’s the only place [mums] have, but the dads don’t have a place so, that is something that we’ve said quite a lot, it’s too bad the dads, or that there isn’t like a little parent lounge or something, [where we] can go have a cup of tea and a chat.” (Participant 3)

Facing the future

Thinking about discharge

At the time of the interviews all of the parents' infants were moving towards discharge from the surgical NICU. Parents felt mixed emotions about their infant's discharge; excitement and pleasure that their infant was well enough for this was paired with fear and anxiety about how they would manage their infant's care:

“How do you feel about going home? Looking forward to it but scared at the same time, just because he's on the monitors and stuff and you know if something's annoying him and his stats drop on his wee monitor, so you know when there's something, but when we go home I won't know. It's a scary thought.” (Participant 5)

“If he's having trouble breathing when there's three nurses in the room and oxygen, you know, but it's another to be... well at home where none of that is [...] so I definitely am nervous and anxious about it, but I'm also like, ‘Well we have to do it at some point’.” (Participant 3)

Parents acknowledged the support and reassurance they gained from ward staff and monitoring equipment and that at home they will have to assume responsibility for ensuring their infant's wellbeing and health.

Hopes for a 'normal' future

A return to home also signified a return to a more normal life for the parents. The parents spoke about their aspirations for the short and longer term and that they were looking forward to normal parenting activities:

“You look forward to different things now, kinda like every other normal person like that, so I just look forward to putting them to their bed an' that, an' [...] changing his bum.” (Participant 1)

Parents also thought ahead to their infant's future and whether they or others would be able to tell that their infant had had a non-typical start to life:

“He has the tiniest incision on his belly, you will never, like nobody will even notice when he’s older. So I feel quite positive about that.” (Participant 2)

However, parents of infants with a higher risk of future complications reported concerns about their infant’s future health and whether they would require further surgery. One parent wondered whether their infant’s health would impact on their parenting style and choices about what they do as a family.

*“How protective over him will I be? Will I wrap him in cotton wool all the time or will I be a bit more, kind of... less worried about him? Will I feel comfortable going on holiday? **Mhm** You know taking him away from hospitals to remote areas [...] You know, how long can he live with his condition? [...] There are [worries], um, but at the same time you just want to trust that he’ll keep getting better and that that’s what’s going to happen, you know.”* (Participant 4)

Discussion

Qualitative research in healthcare facilitates the detailed exploration of people’s personal experiences of a particular condition, treatment or service. Through gaining a greater understanding of people’s experiences services are better placed to provide a service that meets their needs. The international introduction of family-centred care emphasises the importance of involving and providing care for the families of NICU infants (Gooding et al., 2011). The impact of having an infant who requires admission to NICU has been extensively studied (Cleveland, 2008; Jackson et al., 2003; Obeidat et al., 2009; Zelkowitz et al., 2009). Such studies highlight the short- and long-term emotional and psychological impact that NICU admission can have upon parents and their relationship with their infant. The results from this study were largely in keeping with the literature about parental experiences of NICU admission and parents of surgical infants with CHD (Doherty et al., 2009; Harvey et al., 2013). The study expands the limited literature base relating to parents of surgical infants; a need highlighted in a recent literature review of the field (Diffin et al., 2013). This study also adds to the existing literature by examining the qualitative experiences of parents of infants who require surgery for conditions other than CHD.

This research explored the lived experiences of parents who have an infant that required surgery. The interpretation of the interviews led to the identification of five superordinate

themes: being told – the psychological impact of diagnosis; living on the ward; becoming a parent to a critically ill baby; coping and facing the future.

Parents experienced a range of intense emotions at the time of diagnosis, during their infant's NICU admission for surgery and recovery. Parents worried about the adverse consequences that their infant's condition and subsequent need for surgery could have on their infant's health and ultimately their life. Similar experiences were described by mothers of infants who required surgery for CHD in Harvey et al. (2013); these experiences were described in the themes entitled 'intense fluctuating emotions' and 'facing the possibility of my baby dying' (Harvey et al., 2013). In the current study, parents wondered about why their infants required surgery and sometimes blamed themselves or felt guilty about it. By trying to understand why their infant required surgery and seeking information about the unknown and unexpected medical world they encountered, parents attempted to reduce their feelings of uncertainty and anxiety. This is in keeping with existing literature that highlights parents' desire for information about their infant's condition in the NICU to help manage their distress (Cleveland, 2008; Fegran et al., 2008; Harvey et al., 2013). Parents described their experience using strong aversive emotional terms, for example: horrific, traumatic, intense and shocking. Parents' emotional responses to the stressor of having an infant who requires surgery were at times similar to a grief or trauma response, including shock, denial, heightened anxiety and hyper-vigilance. Rates of post-traumatic stress disorder (PTSD) in parents of NICU infants are similar to those in other acute illness and injury populations (for example, paediatric intensive care); with 15% of mothers and 8% of fathers meeting diagnostic criteria for PTSD 30 days after their infant's NICU admission (Lefkowitz, Baxt & Evans, 2010). The sample in Lefkowitz et al. (2010) included parents of NICU infants, but did not specify whether the infants had surgery or not; given that parents of surgical infants share a similar experience to parents of NICU infants it is likely that PTSD is also present in this population.

Parents in this study needed to adjust to becoming parents while spending long periods of time in the NICU. The challenges experienced by parents in this study are consistent with previous research into parental perceptions of the challenges they face when their infant is in a NICU, including the impact of the illness on their parental role and the appearance of the baby (Miles, 1991). Separation and lack of involvement in infant care were particularly challenging for parents in this study, which has also previously been identified as a

challenge for NICU parents (Cleveland, 2008; Wigert, Johansson, Berg & Hellström, 2006). One parent described that their fear about their infant's survival directly affected the development of their attachment or bond with their infant; this is of interest and could warrant further investigation. It may be that this is a more prevalent concern but is one that is difficult for parents to express, therefore, was not frequently reported in this study. The impact of premature birth on the parent–infant relationship and child outcomes (Muller-Nix et al., 2004) including cognitive development (Zelkowitz et al., 2009) has previously been reported; it would be helpful to know whether similar outcomes are also present in a surgical sample, due to parents' perceptions about risk to life. Separation was a significant difficulty for parents in this study, particularly mothers who remained in the maternity hospital whilst their infant was transferred to the children's hospital. Mothers appreciated the photos that they received from the hospital when their infant was transferred; however, their distress remained high. The inability to be physically present and close to their infant and the perception that they were missing out on typical experiences associated with having a baby were particularly difficult for these mothers. The mothers who were separated from their infants reported significant distress during this period, which was exacerbated by sharing the ward with other mothers and their babies. This finding is consistent with existing literature about mothers of NICU infants feeling different to other mothers on the postnatal ward; feeling different led to maternal distress and a struggle to feel that they belonged there (Wigert et al., 2006).

In the region where this study was conducted, all infants who require surgery must transfer from the maternity hospital to the children's hospital for surgery. Some studies have investigated parental experiences of infant transfer; this has typically been on the 'back transfer' of infants from NICU or SCBU to home (e.g. Rowe & Jones, 2008; Griffin & Pickler, 2011) and less frequently on the transfer between wards or hospitals (Hawthorne & Killen, 2006). Research investigating infant transfer between hospitals suggests that the parent-infant separation and the feelings of loss experienced by parents are particularly challenging (Hawthorne & Killen, 2006), which is consistent with the finding in the current study. Hawthorne and Killen (2006) also reported that inter-hospital transfers can cause practical stress for the parents, including the loss of support systems, the requirement to adjust to a new ward and staff and their infant potentially moving further from home. For three of the parents in this study, accommodation was provided in a building adjacent to the children's hospital following the mothers' discharge from the maternity hospital, as

they lived between one to four hours away from the hospital, which alleviated some of these practical stressors.

The study highlights how parents value good communication and timely and accurate information from staff; it is not only the content of this communication but how it is delivered that had a positive impact on parents in this study. Parents reported finding personable, warm and caring staff comforting and containing. There were times when communication was unsuccessful and parents were given conflicting or confusing information or not kept up-to-date with their infant's condition in a timely fashion. Given that parents experience great uncertainty and anxiety about their infant requiring surgery it is important for staff-to-staff and staff-to-parent communications to aim to alleviate this when possible. The finding that parents benefit from clear communication is consistent with existing literature (Cleveland, 2008; Harvey et al., 2013).

Parents described using both problem-focused and emotion-focused approaches to coping with their infant requiring surgery and NICU admission. People tend to use both problem- and emotion-focused approaches when confronted with a stressful situation, the former to manage the troubled person-environment relationship and the latter to manage the emotional distress caused by the situation (Lazarus & Folkman, 1987). It is not possible to quantify from this study what type of coping parents used predominantly and it is recognised that type of coping strategy adopted is likely to change depending on the demands of a situation. However, parents appeared to frequently use emotion-focused approaches to coping, particularly reappraisal or reframing. This is consistent with literature that has investigated parents' coping strategies when they have a surgical infant; studies have found appraisal-based coping is frequently used by parents and is positively associated with parental wellbeing and mental health (Doherty et al., 2013; Rempel & Harrison, 2007). Literature suggests that people tend to use problem-focused coping when situations are perceived to be changeable, whereas emotion-focused coping is utilised in situations that require acceptance (Lazarus & Folkman, 1987). This is in keeping with the parents' frequent reference to needing to accept their situation, as they were unable to change the fact that their infant required surgery. Coping is conceptualised as a dynamic process, involving continuous appraisal and re-appraisal of the shifting person-environment relationship, which may result from external or environmental factors or

internal factors, such as the person's capacity to cope with a given situation (Lazarus & Folkman, 1984, p.142).

Parents identified immediate and long-term hopes and fears for their infant's future health and how they as parents would manage the discharge to home taking into account the added responsibility that they would have for protecting and caring for their infants. Parents also reflected on what they had gained from the experience of having an infant who required surgery and how this would help them to cope with future challenges. In particular, parents spoke about a changed perspective and increased awareness of what is important to them in life, this is consistent with literature regarding changed perspectives and priorities in parents of NICU infants (Jackson et al., 2003).

Limitations

Prior to conducting the interviews the researcher had no information about the infant except that they were in a stable condition. It may have been helpful to gather background information prior to conducting the interviews, for example, the infant's condition, their prognosis and what treatment they received. The researcher may then have been able to explore parental experiences more fully. Yet, lack of information may have helped to locate the parent in an 'expert' role and facilitate a more natural and curious exploration of the parents' experience, as the researcher asked questions about conditions or treatments that they were unfamiliar with. Furthermore, this provided the researcher with the opportunity to explore parents' own understanding of their infant's condition, prognosis and treatment.

IPA design requires a relatively homogenous sample; therefore, the findings of this study are not readily generalisable to a wider population. The inclusion criteria were selected to facilitate recruitment of a relatively homogenous sample, however, the sample was limited as all parents had male infants, and four of the five participants were mothers. The study had aimed to recruit approximately equal numbers of mothers and fathers; however, this did not occur. It is possible that fewer fathers were recruited because they are less frequently on the ward, perhaps due to returning to work, and because fathers may not be as motivated to participate in research. If there had been a longer data collection window it may have been possible to recruit more fathers to the study. As such, from the sample recruited it is not possible to draw out any differences or similarities between mothers' or

fathers' experiences, which had been an initial aim of the study and worth exploration in future studies.

A further limitation of the study is that the researcher is inexperienced in the use of IPA. The second rating of a transcript and discussion regarding identification of emergent and superordinate themes with supervisors was undertaken to try and reduce the impact of the researcher's inexperience with this methodology. Involving participants in checking the analysis may have further improved the validity of the analysis; however, due to time restraints this was not practicable.

Implications

The findings of this study have implications for policy makers and service managers who are involved in the design and delivery of services that care for infants who require surgery and their families. In view of the newly established Neonatal Managed Clinical Networks in the United Kingdom, which involve more infants being transferred between hospitals - recognition of the distress and anxiety that separation from their infant causes parents is essential to consider. Services may need to find more effective ways of communicating with and involving parents in their infant's care, and aim to support them to gain proximity to their infants. Knowledge of the stressors experienced by parents and how they cope with them will be of interest to clinicians from a range of disciplines who provide care and support to families of surgical infants. As a result, the project's findings may inform and improve future care provision for families of surgical infants.

Conclusion

The results of this study suggest that having an infant who requires surgery is an emotionally challenging time for parents. This study provides insight into how parents experience this situation, in particular, it highlights some of the challenges associated with this experience and strategies and approaches that parents use to cope with it. This research described parental experiences using five main themes: being told – the psychological impact of diagnosis; living on the ward; becoming a parent to a critically ill baby; coping and facing the future. The findings of this study are in keeping with the emerging literature base about parents' experiences of infant surgery. The study adds to the existing qualitative literature base by investigating parental experiences of having an infant who requires

surgery for conditions other than CHD. The experiences of parents of surgical infants remains a relatively under-researched area and therefore would benefit from further investigation, particularly the experiences of fathers as they are under-represented in the research conducted to date.

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CHAPTER THREE: ADVANCED CLINICAL PRACTICE I

“Getting the balance right” – a developmental perspective on communicating formulations.

Abstract

This reflective account describes, from a developmental perspective, my experience of communicating formulations throughout Doctoral training in Clinical Psychology. In this account I reflect on a complex case from my first year placement and consider my experience of communicating a formulation with the client and the multidisciplinary team. I also review more recent experiences from my current third year advanced clinical practice placement. This has enabled me to identify areas of development as well as situations to be mindful of and skills to continue to develop during the remainder of training and post-qualification. Using several models of reflection to guide and structure the account, I have been able to explore and make sense of my experiences, reactions and actions. Gibbs’ model of reflection (1988) and Kolb’s experiential learning cycle (1984) have guided my reflections and ensured that my development and the experience of future clients will benefit from this process, by highlighting the importance of learning through reflection and applying this learning in future situations. Formulation is a core competency of Clinical Psychologists (BPS, 2011).

CHAPTER FOUR: ADVANCED CLINICAL PRACTICE II

Clinical Psychology and the role of the scientist-practitioner.

Abstract

This reflective account describes, from a developmental perspective, my experience of conducting research throughout my Doctoral training in Clinical Psychology. In this account I reflect on the service-based evaluation project I completed in my first year of training; where I consider my experience of working with difficult data and feeding back the project findings to a multidisciplinary team. I also review a more recent experience of conducting a research interview for my thesis, which led to me reflecting on some of the challenges of conducting research with potentially vulnerable participants and the value of clinical skills when conducting research with this population. Reflecting on my research experience throughout training has enabled me to determine areas of strength and development as well as potential areas and situations to be mindful of when developing research projects as a qualified Clinical Psychologist. Using several models of reflection to guide and structure the account I have been able to explore and make sense of my experiences, reactions and actions. Kolb's experiential learning cycle (1984) has guided my reflections and ensured that I have been able to use this opportunity to further develop my understanding of research-planning in the health service, while acknowledging both the purpose and benefits of clinician-led research. My learning gained through completing this reflection will be applicable to future situations in a post-qualification role. Research knowledge and skills are considered core competencies of Clinical Psychologists (HCPC, 2012).

APPENDICES

Appendix 1. Guidelines for Submission to the Journal of Reproductive & Infant Psychology

Taylor & Francis Style No. 2 (single column, titles centred)	
Running heads	<i>(verso)</i> J. Smith and P. Jones or J. Smith et al. if 3 or more authors. If J.B. Smith then initials are closed up <i>(recto)</i> Journal Title centred on pages
Article type (when needed)	RESEARCH ARTICLE bold caps, centred
Title	Bold, first word and proper nouns cap only centred
Authors	An Author and Another Author (initials closed up if J.B. Smith) centred
Affiliation	^a Department, University, City, Country; ^b Department, University, City, Country centred
Received dates	<i>(Received 20 July 2011; accepted 17 August 2012)</i> After affiliation, centred
Abstract	Text smaller, indented both sides Centred
Keywords	Keywords: word; another word; lower case except names Position aligned with abstract, same size as abstract
Correspondence details	Given as footnote on page 1* *Corresponding author. Email: xxxxxxxx ranged left, no indent. Postal address not included in footnote. If there is only one author, use *Email: xxxxxxxx
Headings	A. Bold initial cap only B. Bold italic initial cap only C. <i>Italic initial cap only</i> D. <i>Italic initial cap only</i> . Text runs on All ranged left, numbers to be included if supplied, no indent below.
Paragraphs	Indented
Tables	(Table 1) in text. Table 1. Title initial cap only. (ranged left above table) Note: This is a note. (ranged left under table)
Figures	(Figure 1) in text. Figure 1. Caption initial cap only. (ranged left under figure) Note: This is a note. (ranged left under figure)
Permissions statement for third-party figure and table captions	If the rightsholder has supplied text for this purpose, use their text. Otherwise, insert the rightsholder's name within the square brackets: © [Rightsholder]. Reproduced by permission of xxx. Permission to reuse must be obtained from the rightsholder.
Displayed quotations	Indented left and right, smaller font (over 40 words, or when appropriate)
Lists	(1) for numbered lists Bullets if wanted
Equations	Equation (1) in text Centred
Acknowledgements	A heading. Goes before notes, bio notes and refs Text smaller
Funding	A heading. Goes after Acknowledgements Text smaller Funding agency written out in full. Grant number in square brackets. Multiple grant numbers separated by comma and space. Agencies separated by semi-colon, e.g. This work was supported by the Wellcome Trust [grant number]. This work was supported by the Wellcome Trust [grant number], [grant number]; Cancer Research UK [grant number]; another

	funder [grant number].
Notes	Notes (A heading) 1. This is a note. 2. This is another note. Text smaller
Notes on contributors Not all journals require this – please see the relevant instructions for authors page	Notes on contributors (A heading) First author details. Line space Second author details. Goes after Acknowledgements, before refs Text smaller
Appendix	Appendix 1. Title if given (A heading) Goes after References Text smaller
Spelling preferences	Please consult the instructions for authors page for the journal.
Punctuation	Please consult the instructions for authors page for the journal.
Dashes	Spaced en rules for parenthetical dashes Use en rule between spans of numbers (e.g. 20–40), including page numbers in references
Numbers and units	Numbers: spell out one to nine, then 10, 1000, 10,000 10% (except at start of sentence) Units: follow author
Dates	4 October 2005 in the twenty-first century in the 1970s
Editorial	Editorial (as title) If editorial has a title, use EDITORIAL (section heading) Title of editorial Editor Name <i>Affiliation if wanted</i>
Other article types	Follow style for main articles
Book reviews	BOOK REVIEWS (as section heading) Book title: all bold , by Author and Author / edited by Editor, Cambridge, Harvard University Press, 2003, xliii + 584 pp., US\$28.95 (paperback), ISBN 0-95-445440-6 Book title , edited by Editor, Manchester, Manchester University Press, 2010, xv + 340 pp., £24.99 (paperback), ISBN 978-0-719-08154-5 Book title , edited by Editor, Editor and Editor, Abingdon, Routledge, 2009, xvi + 360 pp., \$170 (hardback), ISBN 978-0-415-56085-9 / \$44.95 (paperback), ISBN 978-0-415-56086-6 / \$35.96 (ebk), ISBN 978-0-415-46087-3 Book title , by Author, Lanham MD, Lexington Books, 2008, 542 pp., £59.95 (hardback), ISBN 978-0-739-11434-6 / £27.95 (paperback), ISBN 978-0-739-11435-3 Reviewer's Name <i>Affiliation</i> <i>Email</i> (c) year, Reviewer Name References go before reviewer details Next review follows after a space

	No copyright line on first page of reviews
Obituary	<p style="text-align: center;">OBITUARY (section heading) Name and dates if given (as title)</p> <p style="text-align: right;">Author Name <i>Affiliation</i> <i>Email</i></p>

Appendix 2. Walsh & Downe (2006) Recommendations for Appraising Qualitative Research

Scoring: Each study was reviewed and given a score for each of the essential criteria. If the criteria was not met the study was awarded a score of 0, if the criteria was partially met a score of 1 was awarded and if the criteria was fully met the study was awarded a score of 2. The maximum possible score is 24.

<u>Stages</u>	<u>Essential Criteria</u>	<u>Specific Prompts</u>	<u>Score</u> 0=not present 1=partially met 2=fully met
1. Scope and purpose	Clear statement of and rationale for research questions/aims/purpose	<ul style="list-style-type: none"> • Clarity of focus demonstrated • Explicit purpose given • Link between research and existing knowledge demonstrated 	•
	Study thoroughly contextualised by existing literature	<ul style="list-style-type: none"> • Evidence of systematic approach to literature review, location of literature to contextualise the findings or both 	•
2. Design	Method/design apparent and consistent with research intent	<ul style="list-style-type: none"> • Rationale given for use of qualitative design • Discussion of epistemological/ ontological grounding • Rationale explored for scientific qualitative method • Discussion of why particular method chosen • Setting appropriate 	•
	Data collection strategy apparent and appropriate	<ul style="list-style-type: none"> • Appropriate data collection methods? • Were they likely to capture the complexity/diversity of experience and illuminate context sufficiently? • Was triangulation of data sources used if appropriate? 	•

Appendix 2. Walsh and Downe (2006) Recommendations for appraising qualitative research, *continued*

<u>Stages</u>	<u>Essential Criteria</u>	<u>Specific Prompts</u>	<u>Score</u> 0=not present 1=partially met 2=fully met
3. Sampling strategy	Sample and sampling method appropriate	<ul style="list-style-type: none"> • Selection criteria and sampling strategy detailed • Justification for sampling strategy given • Thickness of description likely to be achieved from sampling • Any disparity between planned and actual sample explained 	•
4. Analysis	Analytic approach appropriate	<ul style="list-style-type: none"> • Approach made explicit • Was it appropriate for the qualitative method chosen? • Was data managed by software package or hand, and why? • Discussion of how coding systems/conceptual frameworks evolved • How was the context of data retained during analysis • Evidence that the subjective meanings of participants were portrayed • Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance • Research participant involvement in analysis? • Evidence that data saturation occurred or discussion/rationale if it did not • Evidence that deviant data was sought, or discussion/rationale if it was not 	•

Appendix 2. Walsh and Downe (2006) Recommendations for appraising qualitative research, *continued*

<u>Stages</u>	<u>Essential Criteria</u>	<u>Specific Prompts</u>	<u>Score</u> 0=not present 1=partially met 2=fully met
5. Interpretation	Context described and taken account of in interpretation	<ul style="list-style-type: none"> • Description of social/physical and interpersonal contexts of data collection • Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena 	<ul style="list-style-type: none"> •
	Clear audit trail given	<ul style="list-style-type: none"> • Sufficient discussion of research processes such that others can follow 'decision trail' 	<ul style="list-style-type: none"> •
	Data used to support interpretation	<ul style="list-style-type: none"> • Extensive use of field notes entries/verbatim interview quotes in discussion of findings • Clear exposition of how interpretation led to conclusions 	<ul style="list-style-type: none"> •
6. Reflexivity	Researcher reflexivity demonstrated	<ul style="list-style-type: none"> • Discussion of relationship between researcher and participants during fieldwork • Demonstration of researcher's influence on stages of research process • Evidence of self-awareness/insight • Documentation of effects of the research on researcher • Evidence of how problems/complications met were dealt with 	<ul style="list-style-type: none"> •

Appendix 2. Walsh and Downe (2006) Recommendations for appraising qualitative research, *continued*

<u>Stages</u>	<u>Essential Criteria</u>	<u>Specific Prompts</u>	<u>Score</u> 0=not present 1=partially met 2=fully met
7. Ethical dimensions	Demonstration of sensitivity to ethical concerns	<ul style="list-style-type: none"> • Ethical committee approval granted • Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants • Evidence of fair dealing with all research participants • Recording of ethical dilemmas met and how resolved • Documentation of how autonomy, consent, confidentiality, anonymity were managed 	<ul style="list-style-type: none"> •
8. Relevance and transferability	Relevance and transferability evident	<ul style="list-style-type: none"> • Sufficient evidence for typicality specificity to be assessed • Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies • Discussion of how explanatory propositions/emergent theory may fit other contexts • Limitations/weaknesses of study clearly outlined • Clearly resonates with other knowledge and experience • Results/conclusions obviously supported by evidence • Interpretation plausible and 'makes sense' • Provides new insights/ increases understanding • Significance for current policy and practice outlined • Assessment of value/empowerment for participants • Outlines further directions for investigation • Comments if aims/purpose were achieved 	<ul style="list-style-type: none"> •

Appendix 3. MRP Proposal



Research Proposal

Title: An examination of parents' experiences of having an infant who requires surgery.

Background

In Scotland there are approximately 58,000 births per year, and of these infants 11.4% will require extra care (ISD, 2013). For some of these infants extra care will include surgery. Research to date has tended to focus on the experiences of parents of infants in the Neonatal Intensive Care Unit, with less known about parents' experiences of infant surgery and how they manage the required transition between hospitals for surgery. The management of transitions between hospitals for this vulnerable population is increasingly topical in view of the establishment of the neonatal managed clinical networks and the implementation of a new model of neonatal care in which there will be increased movement of infants between hospitals providing neonatal care at different levels (The Scottish Government, 2009).

Aims

To explore the experiences of mothers and fathers who have an infant that requires surgery soon after birth and how they cope with this experience.

Methods

Qualitative semi-structured interviews will explore both mothers' and fathers' experiences of having an infant who requires surgery. Sample size will be 10 participants. The data will be analysed using Interpretative Phenomenological Analysis (IPA).

Applications

It is likely that this project will enhance clinician understanding of parents' experiences of having an infant who requires surgery and inter-hospital transfer. It may provide some insight into the challenges of this experience, how parents cope in this situation and consequently the findings may inform future care provision.

Introduction

The birth of an infant is a significant life event, which has a multifaceted impact on a family who must adapt to their new arrival. In the year ending March 2012 there were 57,911 live and stillbirths in Scotland (ISD, 2013). Of the total live infants born across Scotland annually, approximately 11.4% require some additional care, either in a Neonatal Intensive Care Unit (NICU), High Dependency Unit (HDU) or Special Care Baby Unit (SCBU). In the Greater Glasgow and Clyde (GG&C) NHS board it was estimated that 1,765 infants required extra care in a 12-month period (ISD, 2013).

There is a wealth of literature available on parents' experiences of having an infant in a NICU, which report that parents experience high levels of distress, anxiety, depression and a sense of loss and grief (E.g. Obeidat, Bond & Callister, 2009; Cleveland, 2008; Fegran et al., 2008). Parents also reportedly fluctuate between feelings of inclusion and exclusion from their infants care (Obeidat, Bond & Callister, 2009; Cleveland, 2008). The main sources of stress for parents have also been highlighted, including the impact that infant illness has on parental role, infant appearance and behaviour (Miles, 1991). Within literature about parental experiences, fathers have generally been included to a lesser degree (Fegran et al., 2008; Carter et al., 2005). Some research suggests that fathers report a different experience in the NICU to mothers. Mothers have reported feeling that they have more responsibility and control of their infant's care and a need to be confirmed as a mother, whereas fathers described confidence in letting staff care for their infant (Jackson, Ternstedt & Schollin, 2003) and that they strive to find a balance between family life and work (Pohlman, 2005).

Infants may require additional care for a number of reasons, including prematurity (which is defined as any infant born under 37 weeks gestation), poor intrauterine growth or congenital diseases. Of these infants requiring extra care some will require surgery, which may include neurosurgery, gastrointestinal, renal, ear, nose and throat or orthopaedic surgery. Diffen et al.'s (2013) literature review (N=4 studies) reported that infants requiring neonatal surgery have longer-term complex health and developmental needs than non-surgical infants, which may lead to increased risk of their families experiencing stress. Limited literature is available regarding the experiences of parents of infants who require surgery, yet the value that research in this area could have in improving healthcare outcomes for the whole family has been emphasised (Diffen et al., 2013; Harvey et al., 2013). Of the research conducted with parents of surgical infants most have utilised quantitative methodologies e.g. Doherty et al. (2009). The limited number using qualitative

methodologies have some limitations, e.g. Harvey et al. (2013) used a retrospective design and did not include fathers in their research.

In the region where this study will be conducted, all infants who require surgery will have been transferred from a maternity hospital to the hospital where they have surgery. This transfer could be from within or out-with the health board and following surgery the infant may also be transferred back to the referring hospital. Current literature has focussed on the 'back transfer' of infants from NICU or SCBU to home (e.g. Rowe & Jones, 2008; Griffin & Pickler, 2011) and less on the transfer between wards or to a surgical ward. In these circumstances the provision of information, preparation of parents and increased parental participation were perceived to reduce parental anxiety levels. The transition to home can enable parents to feel that they have attained a parental role (Hutchinson, Spillett & Cronin, 2012) but it can also be a time associated with increased stress (Rowe & Jones, 2010). The transfer of an infant to a surgical ward and the subsequent intensive care they require will also be likely to impact on the parents' perception of their role as a parent.

Research Aims

The primary aim of this project is to explore the experience of parents who have an infant that requires surgical intervention within the first two months following birth. The project will aim to:

1. Explore the challenges faced by parents of infants requiring surgery, including the experience of transfer to another hospital.
2. Explore the ways in which parents cope with the experience of having an infant who requires surgery.

Design and method

Participants

Participants will be parents (mothers and fathers) of infants who attend the Royal Hospital for Sick Children (RHSC), Yorkhill, for surgical interventions within the first two months following birth. The project will aim to recruit a sample of ten parents. Mothers and fathers of the same infant will be invited to participate individually in the research; however, if only one parent or a single parent chooses to participate they will be included in the study.

Interpretative Phenomenological Analysis (IPA) research uses purposive samples of participants to gain insight into the particular phenomena under study (Smith & Osborn, 2008; Smith et al. 2009). Generally researchers aim to identify a fairly homogenous

sample, however, Smith et al. (p.49, 2009) suggest that it may be useful to split the sample to enable the phenomenon to be understood from different perspectives. If roughly equal numbers of mothers and fathers are recruited the data will be analysed as two separate samples; this will enable the project to explore mothers' and fathers' different perspectives of the experience.

Justification of Sample Size

As this study will use a qualitative approach to the research question and aims to describe in detail the parent's experience the sample size will be small. Smith et al. (p. 51-52, 2009) suggest that a sample size of between four and ten interviews is typical for qualitative research conducted as part of a professional doctorate. The sample size should also aim to enable data saturation to occur; data saturation occurs when the most relevant themes are identified in the data. Guest, Bunce & Johnson (2006) suggest that in studies with a relatively homogenous sample conducting six to twelve interviews should be sufficient to reach data saturation. Additionally, Fegran et al. (2008) who conducted qualitative research with parent dyads used a sample of six couples (i.e. 12 participants). Taking these factors into account the proposed sample size for this project will be ten participants.

Inclusion and Exclusion Criteria

Inclusion Criteria

- Parents of infants who require surgical intervention, within the first two months following birth.
- Parents of infants who have had surgery at RHSC, Yorkhill.
- Single births, as the presence of two or more infants is likely to impact on the parent's experiences, in terms of stress and available time to spend with each infant.

Exclusion Criteria

- Parents of infants who are not likely to survive. These infants will be identified through liaison with the medical team on the ward.
- Young parents less than 18 years.
- Parents who do not speak English as their first language.

Recruitment Procedures

Participants will be recruited from Wards 2B and 3B, at RHSC, Yorkhill. The project's field supervisor works in the Maternity and Neonatology Clinical Psychology Service, which provides input for GG&C Maternity Hospitals and the RHSC Neonatal Wards with whom

they have a close working relationship. The Clinical Psychologist who provides input for Ward 2B has reviewed the research proposal and has agreed to support recruitment.

Potential participants will not be identified or approached by the Principal Researcher; they will be identified and then approached by either the Clinical Psychologist or Ward Sister working in Ward 2B. The Clinical Psychologist and Ward Sister who will identify potential participants are members of a team who would have access to the infant's medical records as part of normal practice. As NHS staff at the RHSC, Yorkhill, they are bound by NHS and professional recommendations and regulations regarding patient confidentiality and will not share any identifiable information unnecessarily. Potential participants will be approached approximately four or five days after their infant has had surgery and whilst they remain an inpatient. Consideration has been given as to when to approach parents and it is thought that four or five days following their infant's surgery will be appropriate, as this is when families would routinely be offered a Clinical Psychology appointment as part of standard care. It is anticipated that this time scale will also enable parents to provide a detailed account of their experiences. The Neonatal Surgery Ward receives approximately 30 new referrals each month and due to the medical support required by the infants it is likely that they will remain there for at least two weeks. As such, it is anticipated that it should be feasible to complete recruitment and data collection within the proposed four to five month period. Of the limited research conducted with parents of surgical infants some have involved data collection within the first few months following the infant's birth, however, research in this area has mostly employed quantitative (e.g. Doherty et al., 2009) rather than qualitative methodologies (e.g. Rempel & Harrison, 2007). Within research about parental experiences in the NICU some qualitative studies have also recruited parents whilst their infant remains an inpatient, e.g. Hollywood & Hollywood (2011) and Heermann, Wilson & Wilhelm (2005). The completion of these studies suggests that some parents of infants requiring intensive care are willing to participate in qualitative research at this stage of their infant's life.

Each potential participant who is identified as meeting the inclusion criteria will be provided with written information about the study to read in their own time by the Clinical Psychologist or Ward Sister. Each potential participant will receive an envelope containing the Participant Information Leaflet (Appendix 1), Participant Response Form (Appendix 2) and envelope for returning the completed Participant Response Form. The Clinical Psychologist or Ward Sister will pass the envelope to the potential participants directly or place it on the table next to their infant's cot, which is where written correspondence and messages would typically be left for the parents. Therefore, each mother and father who

is asked to participate in the study will receive an information leaflet, an individual response form and envelope to return the completed forms in.

The participant response letter is to be returned to the Ward Sister or Clinical Psychologist by the parent if they are interested in taking part in the study. The completed form will then be passed to Ruth Hind, Principal Researcher, who will contact the parent to answer any questions they may have and to arrange a time to meet to complete the participant consent form (Appendix 3) and interview. Parents who have returned the participant response form will be contacted a minimum of 24 hours after they have received the participant information leaflet and participant response form. Those parents who do not opt-in will not be contacted and their personal contact information will not be available to the research team.

The Principal Researcher will then contact the potential participant to provide them with the opportunity to ask any questions that they may have about the research. This contact will also be used to arrange a meeting with the parent to complete the participant consent form and interview if they agree to this. Contact will be made with potential participants by a method that they have selected as acceptable to them when they completed the participant response form, e.g. telephone call, meeting in person or a letter.

A maximum of two attempts will be made to contact the potential participant once they have expressed interest in participating in the study (i.e. returned the completed participant response form). If a potential participant does not respond to either attempt it will be presumed that they do not wish to take part in the research. If they do respond positively to contact by the Principal Researcher then further contact will be made to allow for the interview appointment to be arranged.

When the parent attends the appointment with the Principal Researcher, Ruth Hind, it will be in a private room on the ward (Ward 2B or 3B, RHSC, Yorkhill) where their infant is an inpatient. The potential participant will have the opportunity to ask any questions they may have about the research project prior to completing the consent form and the interview (Appendix 5).

The staff on the ward where the infant is an inpatient will be informed by letter if an infant's parent or parents have agreed to take part in the research (Appendix 4). Consent will be sought from parents to include their infant's name and date of birth in the letter to the ward.

As the project is interested in mothers' and fathers' experiences the project will aim, where possible, to recruit families with a mother and father involved in the care of the infant. Mother and father dyads will be offered separate interviews to allow them to express their personal experience. It is anticipated that there may be more mothers than fathers available to attend the interviews due to practical issues. However, the study will still aim to recruit fathers and if possible analyse the data in two groups to explore their different perspectives on the experience. Fegran et al. (2008) used a similar approach to this in a qualitative study to explore separately mothers' and fathers' experiences of attachment with their preterm infants.

Measures/Source of Data

The main source of data will be exploratory semi-structured interviews with parents of infants who require surgery. Interviews will be completed flexibly; using prompts and probes to fully explore the participants' experience. The researcher will aim to build and maintain rapport to encourage the participant to fully express their views on their experience.

Some basic demographic data will be collected about the participants, including: age, gender, marital status and number of children. Anonymised demographic information about the infant will also be collected, including: gestational age (in weeks and days), their birth weight, reason for surgical admission, age at time of surgery and age at the time of the interview (both in weeks and days).

Design

The project will be qualitative in design using IPA. IPA aims to explore in detail a participant's experience, understanding and the meaning they give to situations or events that they experience (Smith & Osborn, 2008). Semi-structured interviews lasting approximately sixty minutes will be conducted to explore parents' experiences of having an infant who requires surgery in the two months following birth. A review of current literature will inform the structure of the interviews (See Appendix 5 for the Interview Schedule).

The interviews will be recorded using a digital voice recorder and be transcribed verbatim by the Principal Researcher. Following transcription the data will then be analysed. To increase the reliability of the data transcription and analysis it would be beneficial to have a sample of each second-rated.

When the first one or two interviews have been completed the Principal Researcher will transcribe and review them as a pilot to determine whether the interview schedule is effectively eliciting relevant information for the study. At this stage the interview process can be adapted or refined as required.

Data Analysis

The qualitative data collected will be transcribed using IPA protocols and analysed following the recommended procedures (Smith & Osborn, 2008). IPA appears to be an appropriate methodology to use as it aims to explore how people experience and make sense of events or situations that occur (Smith & Osborn, 2008). IPA has been used in a number of other studies that aimed to describe and interpret parents' experiences of their children's ill health, including childhood onset of anorexia nervosa (Cottee-Lane et al., 2004) and adolescent onset of chronic pain (Jordan et al., 2007).

Data analysis will involve several readings of each transcript to identify themes that reflect the participant's experience. Once the initial analysis has been completed one or two of the transcripts will also be analysed by supervising researchers, who will remain blind to the initial themes identified and codes applied. Smith et al. (p. 184, 2009) suggest that if supervisors conduct a "mini audit" of their student's work this can help the student to demonstrate that they are committed to producing quality research with improved validity regarding the interpretation and analysis of data.

Settings and Equipment

A Participant Information Leaflet, Response Form and Consent Form have been created for the study; copies of these documents are available in Appendices 1-3. Interviews will be completed in person in a private room on the ward. A voice recorder, transcription equipment and an encrypted laptop will be required.

Health and Safety Issues

Researcher Safety

The Principal Researcher will conduct the interviews on NHS GG&C property during working hours and will not conduct any home visits. The researcher will be in receipt of regular supervision from the project's field and academic supervisors should any difficulties arise during the course of the study. Local Health and Safety policies will be adhered to.

Participant Safety

If a parent becomes or reports high levels of distress, or if any concerns emerge regarding risk, a member of the clinical team will be informed as soon as possible. If a parent requests further contact from Clinical Psychology, the Clinical Psychologist attached to the ward will provide on-going and seamless input.

Ethical Issues

The project will involve interviewing families who have recently experienced a significant life event, i.e. having an infant who requires surgery. It is possible that the family may not have known that their infant would require surgery during the antenatal period. The researcher recognises that this is likely to be a time of stress and will at all times remain sensitive to this. The project will aim not to include families where the infant is not likely to survive, the Clinical Psychologist or Ward Sister who are involved in recruitment will liaise with ward staff prior to inviting a family to participate in the project in an attempt to control for this. If this does happen or if any concerns are raised through the parent's involvement in the research they will be provided with the opportunity to speak to a Clinical Psychologist. Participants will be asked at the beginning and end of the interview how they are feeling and if the process of being involved in the research has changed their level of distress. This will help to identify if a participant should be offered an opportunity to speak to a Clinical Psychologist within the service.

Participants will be given the choice to participate or not, and they will be provided with information about the nature of the research to enable them to provide written informed consent. Participants will be able to withdraw their consent at any point throughout the research. Ethical approval will be sought from the West of Scotland Research and Ethics Service (WOSRES).

Consideration will also be given to local and national policies and procedures for storing and using confidential information obtained from patients, and ensuring their anonymity in the reporting of the data. Data will be stored anonymously on an encrypted laptop and only be viewed by the researchers who have direct involvement with this project, as outlined in Appendix 3: Participant Consent Form. The recordings will be destroyed following transcription and second rating, where required. The transcribed interview and other research data will be stored according to local policy recommendations.

Timetable

April - November 2013	MRP proposal – refine methodology and literature review. Create draft semi-structured interview schedule. Produce final approved version of MRP proposal.
October-January 2014	Apply to WOSRES and NHS GG&C R&D.
February-March 2014	Begin data collection and pilot transcription and analysis.
March – May/June 2014	Complete data collection and transcription of recordings. Begin analysis of remainder of sample.
June 2014	Complete data analysis of whole sample.
March - July 2014	Write-up report.
July 2014	Submit thesis.

Practical Applications

This project may enhance clinician understanding of parents' experiences of having an infant who requires surgery, which also entails a transfer between hospitals. This will be of interest to clinicians in view of the newly established Neonatal Managed Clinical Networks and the implementation of a new model of caring for sick and premature infants, which will involve more infants being transferred between hospitals. It may provide insight into the stressors associated with infant surgery, hospital transfer and how parents cope with these events. As a result this project's findings may inform future care provision for families who are in a similar situation.

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Appendix 4. Participant Information Sheet



Participant Information Leaflet

Title of Study: An examination of parents' experiences of having an infant who requires surgery.

This leaflet has been given to you by the Neonatal Surgical Unit, at the Royal Hospital for Sick Children, Yorkhill, on behalf of Ruth Hind (Trainee Clinical Psychologist).

I would like to ask you to take a few minutes to read over this information leaflet. My name is Ruth Hind and I am a Trainee Clinical Psychologist with the University of Glasgow. As part of my Doctorate in Clinical Psychology I am undertaking a research project in partnership with the Neonatal Surgical Ward at the Royal Hospital for Sick Children, Yorkhill.

This leaflet is designed to give you all of the information you will need to decide whether you would like to participate in the study. However, if there is anything that I have not mentioned about the study that you would like to discuss, please do not hesitate to contact me.

What is the study about?

I am interested in hearing about mothers' and fathers' experiences of having an infant who has had surgery. I am interested in finding out what parents' find stressful and how they feel about their child being moved from one hospital to another.

Why am I being asked to take part?

You are being asked to take part because you are the mother or father of an infant who has had surgery at the Royal Hospital for Sick Children, Yorkhill. I would like to hear from mothers and fathers of the same infant, where possible. I would also like to hear about your experience if you are a single parent or if only one parent would like to take part in the study. If both parents agree to take part in the study I will meet with you separately so that you are able to tell me about your individual experience.

Do I have to take part?

No, you do not have to take part in the study and deciding not to take part will not affect your infant's care in any way. You can withdraw from the study at any point without this affecting your infant's care.

What would I have to do?

If you agree to take part in the study, the main researcher, Ruth Hind, will contact you to arrange an appointment to complete the interview at the Royal Hospital for Sick Children, Yorkhill. The interview will last for approximately one hour and you will be asked about your experience of having a child who has required surgery and has had to move from one hospital to another. At the start of the interview you will have the chance to ask any questions you have about the study. You will then be asked to sign a consent form to show that you are willing to take part in the study and for the interview to be recorded. This recording will only be used for the purpose of this research.

Who would know I was taking part?

The Neonatal Surgical Unit at RHSC would know that you were taking part in the study, but the information that you provided would be kept confidential. Anything you say will be presented anonymously in the research report so that no one would be able to identify what you in particular had said. If both the mother and father of one infant agree to participate in the research, what one parent said in their interview would not be shared with the other. I would only have to break this confidentiality if I became concerned that you or someone else was at risk of harm. In these circumstances, I would need to share my concerns but I would tell you before I did this.

I would need to know your child's name and date of birth to be able to inform the Neonatal Surgical Unit, RHSC, that you were taking part.

What will happen to the information I provide?

The interview will be recorded. These recordings will be typed up word-for-word (transcribed) and any information that would identify you or your infant will be removed at this stage. Once the recording is transcribed and checked it will then be destroyed. The anonymous transcripts will be stored on an encrypted password protected computer. Only my supervisors (Psychologists working for the Hospital and University) and I will have access to the recordings.

The information will be analysed and presented in the form of a report and submitted to the University of Glasgow in part fulfilment of the Doctorate in Clinical Psychology and for publication in a scientific journal.

Within the report, anonymous quotes of what you have said may be used, but it will not be possible to identify who said this. All participants will be provided with a summary of the results if they would like them.

Are there any benefits to taking part?

There are no direct benefits to you or your infant if you take part in this study. However, you may find it beneficial to speak to someone about your experience and if at the end of the interview you would like more time to talk to a Clinical

Psychologist about your experience I can help to arrange this for you. The information that you provide will add to our understanding of parents' experiences when their infant requires surgery. If this study were published in a scientific journal, it would contribute to the wider research literature and could inform developments in the psychological care of infants who require surgery and their families.

Are there any down sides to taking part?

It is possible that our discussion may trigger some upsetting thoughts or feelings that are difficult to talk about. If this is the case, and you wish to stop, you can end the interview at any time. If you need a break during the interview this would also be fine. If you would like to be referred to the Clinical Psychologist within Maternity and Neonatology Services, this can be arranged.

Who has reviewed the study?

The study has been approved by the University of Glasgow, the West of Scotland Research Ethics Committee and the NHS Greater Glasgow & Clyde Research and Development Team.

Who do I contact for more information?

You may contact any of the researchers involved in this study if you have further questions about the research. An independent contact person is also available to provide information about this study. The independent contact is Dr Sarah Wilson, who is an experienced researcher based at the University of Glasgow. She has no direct involvement in this study and can provide impartial information and advice about it.

Name	Role	Email address	Telephone number
Ruth Hind	Primary Researcher	r.hind.1@research.gla.ac.uk	0141 211 0607
Dr Alison Jackson	Academic Supervisor	Alison.Jackson@glasgow.ac.uk	0141 211 3917
Dr Joan Burns	NHS Supervisor	Joan.burns@ggc.scot.nhs.uk	0141 232 4333
Dr Sarah Wilson	Independent Contact	Sarah.wilson@glasgow.ac.uk	0141 211 3921

What do I do now?

If you are interested in taking part in the study, please complete the attached form and return it in the envelope to either the Ward Sister or Clinical Psychologist who gave you the information about the research. I will then contact you by telephone, in person on the ward or by letter to answer any questions that you may have about the study and to arrange an appointment for the interview. When we meet I will ask you to sign a consent form to show that you have read and understood the information provided to you and that you agree to take part in the study.

Thank you for taking the time to read this leaflet and for any further input you may wish to have.

Ruth Hind
Trainee Clinical Psychologist

Contact information:

Primary researcher: Ruth Hind, Trainee Clinical Psychologist

Address: Mental Health and Wellbeing, University of Glasgow, Gartnavel Royal
Hospital Academic Centre, 1055 Great Western Road, G12 0XH

Email: r.hind.1@research.gla.ac.uk

Telephone: 0141 211 0607

Appendix 5. Participant Response Form



Participant Response Form

Title of Study: An examination of parents' experiences of having an infant who requires surgery.

My name is _____ and I am interested in finding out more about the study described in the *Participant Information Leaflet*.

I am happy to be contacted (*Please tick all that apply*)

- in person on the ward
- by telephone, my number is: _____
- in writing by letter to the ward
- or in writing to another address. My address is:

I am the mother/father of an infant. (*Please circle the appropriate answer*).

Signed: _____

Appendix 6. Consent Form



Consent Form

Title of study: An examination of parents' experiences of having an infant who requires surgery.

Name of researcher: Ruth Hind (Trainee Clinical Psychologist)

Please initial each box:

I confirm that I have read and understood the *Participant Information Leaflet (Version 8, 23/02/2014)* for the above study.

I have had the opportunity to ask questions and have had satisfactory answers to these.

I understand that my participation is voluntary and that I am free to withdraw at any time and without giving any reason. If I do withdraw from the study my or my infant's continued care will not be affected.

I understand that my interview will be recorded and transcribed and I give permission for this.

I understand that only Ruth Hind and the supervising Psychologists (Dr Alison Jackson, University of Glasgow and Dr Joan Burns, Maternity & Neonatology Clinical Psychology Service, NHS GG&C) will have access to the information that I provide.

I understand that my and/or my infant's medical care or legal rights will not be affected by taking part.

I give permission for the researcher to inform the Neonatal Surgery Unit, RHSC of my involvement in this study by letter, which will include my infant's name and date of birth.

I understand that discussion of some topics may be upsetting for me and that the interview can be paused or ended at any time.

I understand that sections of my medical notes may be looked at by the research team, where it is relevant to my taking part in the research, and by authorised representatives of the sponsor and NHS Greater Glasgow and Clyde, for the purposes of audit only. I give my permission for the research team to have access to my records. I understand that anonymised information may be transferred to personnel outwith the research team for analysis.

I would like to receive a summary of the project findings once it is completed (estimated completion date September 2014). Please send a copy to me at the following address:

I agree to take part in the above study.

Name of Participant		Signature
Date		
Name of Researcher		Signature
Date		

Appendix 7. Letter to Team



Mental Health and Wellbeing
University of Glasgow
Gartnavel Royal Hospital Academic Centre
1055 Great Western Road
G12 0XH
Email: r.hind.1@research.gla.ac.uk
Telephone: 0141 211 0607
Date: dd/mm/yyyy

Dear Colleagues,

Re: [insert infant name], D.O.B [insert D.O.B].

I am writing to inform you that _____, the Mother/Father of _____ has agreed to take part in the research study *“An examination of parents’ experiences of having an infant who requires surgery.”*

Yours sincerely,

Ruth Hind

Trainee Clinical Psychologist

Appendix 8. Interview Schedule



Interview Schedule

Perhaps you could start by telling me a bit about yourself and your family.

Can you tell me about your experience of having your baby born and requiring surgery?

Did you know during your pregnancy that your child would require surgery?

If yes, ask about the birth, including:

Can you tell me about the birth of your child?

How did you feel about giving birth knowing that your child would need surgery?

How did you react when you found out that your child required surgery?

How did you feel when you found out that your child required surgery?

What were your concerns when you found out your child required surgery?

What was it like when your infant went into theatre?

Did you have hopes or expectations about what it would be like to be a parent and how have these been similar or different to your experience?

What has it been like since your child has had surgery?

How did you feel after your child had had surgery?

Can you tell me about your experience of being transferred from the maternity hospital where your baby was born to this hospital (RHSC)?

How did you feel when you were told your child would need to be transferred to a different hospital for surgery?

Were you able to come to the hospital with your child?

What was the most difficult thing about the transfer?

How did you cope with the transfer?

What has helped you to cope with this situation?

Is there anything that has helped?

Is there anything that has not helped?

Did you talk to anyone about your experience/feelings in relation to your infant requiring surgery?

What have you been telling yourself/your partner to help you through this experience?

Do you feel you have had chance to come to terms with what has happened?

Does it feel real?

Appendix 9. Supports for Parents Information Sheet



Supports available to parents

Supports within the hospital

Clinical Psychology

There is a **Clinical Psychologist** in the ward who you can talk to about your experience if you want. If you would like to speak to the Clinical Psychologist please let me or another member of the ward staff know and we will be happy to arrange this for you.

Family Support & Information Service

The Family Support & Information Service aims to provide emotional and practical support and information to families attending Yorkhill Hospitals. Please see their contact information below.

Visit them: in the main entrance of Yorkhill Children's Hospital
Telephone: 0141 201 0736/ 0707
Email: family.information@yorkhill.scot.nhs.uk
Opening Hours: Monday to Friday, from 9.00am to 5.00pm.

External supports

BLISS for babies born too soon, too small, too sick

Bliss provide information and support groups for parents of preterm or sick infants, they also have an allocated champion for each maternity hospital in Scotland to help support families.

If you would like to learn more about Bliss or access their service, please see the below contact information.

Web: <http://www.bliss.org.uk/region/scotland/>
Email: scotland@bliss.org.uk
Telephone: Family Support Helpline - Freephone 0500 618140
Monday to Friday 9.00am-9.00pm.

Appendix 10. Approval Letter from WOSRES

Participant Response Form added to documents reviewed and letter re-issued.

WoSRES
West of Scotland Research Ethics Service



Dr Alison Jackson
University Teacher
University of Glasgow
Mental Health and Wellbeing, University of
Glasgow
Gartnavel Royal Hospital Academic Centre
1055 Great Western Road
G12 0XH

West of Scotland REC 4

Ground Floor, Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT
www.nhsqgc.org.uk

Date 19 March 2014
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail Wosrec4@ggc.scot.nhs.uk

Dear Dr Jackson

Study title:	An examination of parents' experiences of having an infant who requires surgery.
REC reference:	14/WS/0028
IRAS project ID:	143600

Thank you for your email of 3 March 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 21 February 2014

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	-	27 February 2014
Participant Information Sheet: Tracked changes	8	23 February 2014
Participant Information Sheet: Clean copy	8	23 February 2014
Participant Consent Form: Tracked changes	8	23 February 2014
Participant Consent Form: Clean copy	8	23 February 2014
Other: List of Support Organisations	1	26 February 2014

Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	-	27 February 2014
REC application	-	22 January 2014
Protocol	7	19 January 2014
Summary/Synopsis	Plain English V7	19 January 2014
Investigator CV	-	26 November 2013
Participant Information Sheet: Tracked changes	8	23 February 2014
Participant Information Sheet: Clean copy	8	23 February 2014
Other: List of Support Organisations	1	26 February 2014
<i>Participant Response Form</i>	7	19 January 2014
Participant Consent Form: Tracked changes	8	23 February 2014
Participant Consent Form: Clean copy	8	23 February 2014
GP/Consultant Information Sheets	7	19 January 2014
Interview Schedules/Topic Guides	7	19 January 2014
Other: Health and Safety for Researchers	7	19 January 2014
Other: Health and Safety Form	7	19 January 2014
Other: Ruth Hind's CV	-	13 December 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/WS/0028

Please quote this number on all correspondence

Yours sincerely



Ms Evelyn Jackson
Committee Co-ordinator

Copy to: *Emma-Jane Gault, R&D Office, Tennent Building, Western Infirmary*
Ms Joanne McGarry, R&D Office, Tennent Building, Western Infirmary

Appendix 11. Approval Letter from NHS GG&C Research & Development



Coordinator/Administrator: JMcG/ LR
Direct Line: 0141 211 8548
E-mail: Joanne.McGarry@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor, 38 Church St
Glasgow
G11 6NT

1st April 2014

Ms Ruth Hind
Trainee Clinical Psychologist
Mental Health & Wellbeing
Gartnavel Royal hospital
1055 Great Western Road
Glasgow
G12 0XH

NHS GG&C Board Approval

Dear Ms Hind

Study Title: An examination of parents experiences of having an infant who requires surgery.
Chief Investigator: Dr Alison Jackson
GG&C HB site: RHSC
Sponsor: NHS GG&C Health Board
R&D Reference: GN14NN124
REC Ref: 14/WS/0028
Protocol no: V7 dated 19/01/14

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information related solely to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
 - a. Recruitment Numbers on a monthly basis
 - b. Any change of staff named on the original SSI form
 - c. Any amendments – Substantial or Non Substantial
 - d. Notification of Trial/study end including final recruitment figures
 - e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely

A handwritten signature in black ink, appearing to read 'Joanne McGarry', with a long horizontal flourish extending to the right.

Joanne McGarry
Research Co-ordinator

CC: Dr Alison Jackson, Chief Investigator, Glasgow.

Appendix 12. Minor Amendment 01 WOSRES Approval

WOSRES
West of Scotland Research Ethics Service



Dr Alison Jackson
University Teacher
University of Glasgow
Mental Health and Wellbeing, University of Glasgow
Gartnavel Royal Hospital Academic Centre
1055 Great Western Road
G12 0XH

West of Scotland REC 4

Ground Floor, Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT
www.nhsqgc.org.uk

Date 13 May 2014
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail Wosrec4@ggc.scot.nhs.uk

Dear Dr Jackson

Study title: An examination of parents' experiences of having an infant who requires surgery.
REC reference: 14/WS/0028
Amendment number: AM01
Amendment date: 12 May 2014
IRAS project ID: 143600

Thank you for your letter of 12 May 2014, notifying the Committee of the following amendment:

- Change to location of study and minor changes to Protocol.

The Committee does not consider this to be a "substantial amendment", as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Notification of a Minor Amendment	AM01	12 May 2014
Protocol	9 - clean copy	09 May 2014
Protocol	9 - tracked changes	09 May 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

14/WS/0028:

Please quote this number on all correspondence

Yours sincerely

A handwritten signature in black ink that reads "Evelyn Jackson". The signature is written in a cursive style with a large initial 'E'.

Ms Evelyn Jackson
Committee Co-ordinator

Copy to:

*Ms Joanne McGarry, R&D Office, Tennent Building, Western
Infirmary
Ms Ruth Hind*

Appendix 13. Minor Amendment 01 NHS GG&C Research & Development Approval

Ruth Hind

From: Reid, Lorraine <Lorraine.Reid2@ggc.scot.nhs.uk>
Sent: 16 May 2014 12:17
To: Ruth Hind
Cc: Alison Jackson
Subject: R&D Reference: GN14NN124 - Minor Amendment dated 09/05/14

Dear Ms Hind

Study Title: An examination of parents experiences of having an infant who requires surgery.
Chief Investigator: Dr Alison Jackson
GG&C HB site: RHSC
Sponsor: NHS GG&C Health Board
R&D Reference: GN14NN124
Amendment: Minor, dated 12/05/14
Protocol no: V9 dated 09/05/14

I am pleased to inform you that R&D have reviewed the above study Amendment and can confirm that Management Approval is still valid for this study.

Reviewed Documents:	Version	Dated
Notification of a Minor Amendment letter	Not versioned	12/05/14
Protocol	V9	09/05/14
REC Acknowledgement Letter	Not versioned	13/05/14

I wish you every success with this research project.

Yours sincerely

Research & Development

R&D Management Office
1st Floor, Tennent Institute
Western Infirmary
Glasgow
G11 6NT
Tel: 0141 211 6372
Please visit our website for further information
: www.nhsggc.org.uk/r&d

P Please consider the environment before printing this e-mail or its attachment(s)

NHSGG&C Disclaimer

The information contained within this e-mail and in any attachment is confidential and may be privileged. If you are not the intended recipient, please destroy this message, delete any copies held on your systems and notify the sender immediately; you should not retain, copy or use this e-mail for any purpose, nor disclose all or any part of its content to any other person.

All messages passing through this gateway are checked for viruses, but we strongly recommend that you check for viruses using your own virus scanner as NHS Greater Glasgow & Clyde will not take responsibility for any damage caused as a result of virus infection.
