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# A Qualitative Study of Fathers' Experiences of a Scottish Neonatal Intensive Care Unit

#### **And Clinical Research Portfolio**

#### Volume 1

(Volume 2 bound separately)

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Submitted in partial fulfilment of the requirements for the degree of

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# Chapter 1: Systematic review

The Support Needs of Fathers Whose Infants are Cared For in a Neonatal Intensive Care Unit: a Qualitative Systematic Review.

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#### Abstract

Objectives: This review aims to identify and synthesise themes from qualitative studies that explore fathers' experiences in the neonatal intensive care unit with the objective of clarifying fathers' support needs.

Methods: A meta-ethnographic approach was employed. The databases CINAHL, PsychINFO, Psychology and Behavioural Sciences, EMBASE and MEDLINE were searched to identify qualitative studies published between 1998 and 2013. Eight studies were identified from a possible 150. Reference lists from these eight studies were hand searched, and each study was quality assessed using a qualitative assessment framework. Papers that did not meet essential quality criteria were removed. Five studies were identified for inclusion.

Results: Six themes were identified: 1) on the sideline, 2) from disconnected to connected as a father, 3) juggling multiple demands', 4) 'anxious pre-occupation with mum and baby, 5) socio-emotional support, and 6) information sharing: the double-edged sword.

Conclusion: The findings of this review suggest that the constructs of support included within an existing conceptual model of parents' support needs (the Nurse Parent Support Model) are relevant for fathers of infants in the neonatal intensive care unit.

The findings, however, also identified additional support needs which were not included in that model, indicating that a revised model with additional supports would be helpful.

Finally, the findings indicate how these constructs of support could be provided in clinical practice to promote parent and infant wellbeing.

Keywords: fathers' experience, meta-ethnography, Neonatal Intensive Care Unit, NICU, Qualitative research.

#### Introduction

Parents of infants admitted to neonatal intensive care units (NICUs) often experience significant distress [1]. Such distress can have harmful effects on infants' development and family functioning [2,3]. Family Centred Care (FCC) is "a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognised as care recipients" [4, pp1318].

In the NICU, one focus of FCC is assisting families to manage the stress, fear and altered parenting roles associated with this situation [5]. The importance of adopting a FCC approach in the NICU has been emphasised by research highlighting the association with FCC and reduced stress for both infants [6] and parents [7]. Therefore, it seems important that healthcare professionals working in the NICU understand the support needs of *both* parents in order to provide effective FCC and minimise their distress and any detrimental effects on family functioning.

To the author's knowledge, no model of parents' support needs is currently used in practice in NICUs. The Nurse Parent Support Model (NPSM) [8], (which is based on House's conceptual definitions of social support [9]), is a conceptual model developed to underpin the Nurse Parent Support Tool (a measure designed to assess parents' perceptions of nursing support during their child's hospitalisation in paediatric and neonatal settings). Although there is as yet no direct research supporting this model, there is strong support for the content validity of the Nurse Parent Support Tool. Specifically, the steps used in constructing the instrument (the use of a conceptual framework, generating items from the literature, use of data from interviews with parents of hospitalised children, and pilot testing with parents and experts [8].

The NPSM envisages the hospitalised child as being embedded within two systems: (1) their parental and family system, and (2) the hospital system.

This model views the provision of support during a child's hospitalisation as being a crucial factor for enabling parents and children to cope. It proposes that four types of support are especially important to meet the needs of parents of hospitalised children: 'informational support', 'emotional support', 'parental esteem support', and 'caregiving support'.

According to House [9] 'informational support' entails advice, suggestions, information giving, and directions. In the NPSM, '**informational support'** is conceptualised as supportive communication and the ongoing sharing of information with parents about: the child's illness, treatment, development, care, behavioural and emotional responses, and needs, and about parental rights and responsibilities during hospitalisation.

'Emotional support', as defined by House, entails behaviours related to trust, affect, concern, and listening. 'Emotional support' in the NPSM similarly includes listening, exhibiting caring behaviours, and being concerned in ways that help parents cope with the illness and other aspects of their lives.

'Esteem support', according to House, involves giving affirmation and feedback, and providing social companionship. Due to the importance of affirming the parental role during a child's illness, however, the NPSM reconceptualised 'parental esteem support' as enhancing, reinforcing, and supporting the parental role.

'Instrumental support', according to House, comprised of assistance of any kind including financial, time, labour, or environmental modifications. Within the NPSM, however, 'instrumental support' was re-conceptualised as 'caregiving support' which involved good quality care for the child.

Two studies have reviewed the literature on parents' experiences in the NICU between 1998-2008 [10,11]. One [10] explored the needs of parents in the NICU and what behaviours support these needs. The other [11]

described parents' experiences when an infant is admitted to the NICU and suggested that, in these circumstances, parents experience depression, anxiety, stress, a loss of control, and fluctuate between feelings of inclusion and exclusion related to their infant's care.

However, the literature reviewed studied mainly mothers' experiences, or mothers' and fathers' experiences simultaneously, often including a higher percentage of mothers.

Available research suggests that mothers' and fathers' support needs in the NICU may differ. For example, stress levels have been found to decrease between birth and discharge for mothers, but increase for fathers [12]. In the NICU mothers focus on caring for their infant, while fathers have been found to prioritise a balance between work and family life [13]. Fathers have also been found to experience stress in relation to their, often increased, responsibilities out-with the NICU [14].

Given these differences a review of the literature looking specifically at fathers' experiences in the NICU is required so that their needs can be better understood.

Qualitative methods provide a thorough understanding of people's experiences, perceptions and pasts in the context of their personal circumstances [15]. Therefore, a systematic review and synthesis of findings from such literature would afford greater insight into the lived experiences and support needs of fathers whose infants require care within a NICU [16].

The present review will elucidate the support needs of fathers in the NICU, which may impact positively on parent and infant wellbeing.

#### **Aims**

To identify and synthesise themes from qualitative studies that explore fathers' experiences in the neonatal intensive care unit, with the objective of clarifying fathers' support needs.

#### Methodology

#### Method of synthesis

Interpretive synthesis aims to achieve conceptual and theoretical development, and hence a greater insight into specific phenomena [17]. This approach fits with the aims of the present review. Meta-ethnography [18] is a form of interpretive synthesis, which involves the translation of studies into one another. This method was chosen as it is considered an optimum method for synthesising qualitative healthcare research, and allows synthesis of studies employing a range of methods [19]. Meta-ethnography involves seven steps which have been elaborated on by Atkins et al., [16]. These steps were followed in the present review (See Table 1).

**Table 1**Seven Steps of meta-ethnography

Stages	Descriptions
1: Getting started and deciding on a phenomenon of the study	The research question was determined
2: Deciding what is relevant to the initial interest	The focus of the synthesis was defined Relevant studies were located and decisions were made about inclusion Quality assessment was conducted
3: Reading the studies	Identified studies were read several times by the author to facilitate their familiarity with the content and detail of each.  The author began to extract 'metaphors' or emerging themes
4: Determining how the studies are related (as the findings might be directly comparable, stand in opposition, or represent a line of argument)	Lists of first and second-order themes were identified and, through synthesis of both participants and authors understandings, third order constructs were identified (See Table 3).  The tables of themes and concepts from each study were compared and a line-of-argument synthesis was taken.
5: Translating studies into one another	Themes from each study were arranged chronologically. Study 1 was compared with study 2, and the synthesis of these papers with study 3 and so on
6: Synthesising translations	This higher order interpretation lead to a line of argument synthesis
7: Expressing the synthesis	The findings were reported in written form

#### Search strategy

The EBSCO host was used to search CINAHL, PsychINFO and Psychology and Behavioural Sciences databases, and OVID was used to search EMBASE and MEDLINE databases. This search employed the use of index terms where possible (EMBASE & MEDLINE), in addition to key terms. Boolean operators (OR and AND) were used to combine search strings.

All searches were completed on 15th November 2013 and included the following terms:

1. neonatal intensive care unit, OR neonatal intensive care, OR NICU, OR preterm infant, OR premature infant, OR extremely premature infant, OR low birth weight infant, OR very low birth weight infant, OR extremely low birth weight infant

AND

- 2. fathers, OR father-infant relations, OR fatherhood, OR paternal AND
- 3. qualitative research, OR interpretive phenomenology, OR thematic content analysis OR personal narratives OR experience\*

Search terms varied slightly according to each databases indexing system. Modifications were made for each database to accommodate the different thesaurus terms. (See Appendix 2 for the exact search terms used for each database):

#### Results of Search

The search produced a total of 228 citations of which 78 were duplicates. The remaining 150 studies were filtered according to the inclusion criteria as follows; 1) study title, 2) abstract, and 3) full text.

#### Inclusion Criteria

- Employed qualitative methodology and analysis to focus on the lived experience of fathers whose infants have been cared for in a NICU.
- Published in a peer-reviewed journal.
- Published in English language.
- Published between 1989-2013.

Eight studies were identified from this search. Their reference lists were hand searched, however no additional studies were found. All eight studies were then assessed for quality.

#### Results

#### Quality Appraisal

Quality assessment of qualitative research has been an area of some controversy. Some have argued that quality checklists are overly prescriptive and risk compromising the unique contribution of qualitative research [20]. For qualitative research to inform healthcare, however, a minimum level of quality assurance is necessary [21] and a number of critical appraisal tools exist. Walsh and Downe [21] reviewed eight such tools but found them excessively detailed. They combined the tools, eliminated non-essential criteria and developed a practical framework (See Appendix 3). This framework was used in the current review.

Each of the following twelve essential criteria was marked as present or absent to determine a profile of strengths and weaknesses: 1) clear rationale, 2) contextualised by literature, 3) method apparent and appropriate, 4) data collection apparent and appropriate, 5) sample and sampling appropriate, 6) analytic approach appropriate, 7) context described and considered, 8) clear audit trail given, 9) data in support of interpretation, 10) researcher reflexivity, 11) sensitivity to ethical concerns, and 12) relevance and transferability.

All researchers made a clear statement of their focus, rationale and research aims. One [22] failed to mention relevant literature; specifically, one of their own publications.

Quality of study design varied across studies; three failed to explicitly state their method [22,23,24], which means that the reader is unable to judge the consistency of their approach with their research intent. The same three studies failed to discuss their epistemological/ontological grounding. All reported appropriate data collection practices. Sample and sampling methods were described by all but one study [24]. However, only two provided a justification for their sampling strategy [25,26]

Most studies described an appropriate analytic approach. In all but one study [25], more than one researcher was involved in analysis. Three studies strengthened their analysis by involving participants [26,27,28]. Only two studies reported reaching saturation [24,25].

Quality of interpretations varied across studies. Contexts were described sufficiently by all but one study [22] which failed to provide a sufficient interpersonal context surrounding data collection, and did not evidence interrogation of their data for completing or alternative explanations. All studies provided a clear account of their analytic process. Although interview data was presented, the data provided by three studies did not adequately support their interpretations [22,23,24]. All but two studies demonstrated researcher reflexivity [22,23].

All studies demonstrated sensitivity to ethical concerns. Evidence of relevance and transferability of findings was provided across all studies, and findings were discussed in the context of previous theory or literature. Limitations and suggestions for future research were generally provided, with two exceptions [23,28].

Walsh and Downe [21] assert that meta-synthesis of methodologically flawed studies may result in flawed conclusions; therefore the decision was taken to exclude papers from the present review that did not adequately address the Framework's twelve essential criteria. The following precautionary measures were taken to prevent minor flaws excluding insightful studies: 1) half of the studies were second-rated by an independent reviewer, with agreement reached through discussion, and 2) all studies that did not meet Walsh and Downe's [21] essential criteria were compared against the Dixon-Woods et al., [29] 'Fatally Flawed' guideline (See Appendix 4). As illustrated in Table 2, three studies did not meet all the essential criteria and were excluded, resulting in five studies being included in the current synthesis (See Fig.1).

**Table 2**Quality assessment following Walsh and Downe's [21] Framework

Essential criteria:	Clear rationale*	Contextualised by literature	Method appropriate*	Data collection appropriate	Sample/sampling appropriate	Analytic approach* appropriate	Context described	Clear audit trail*	Data in support of interpretation*	Researcher reflexivity	Sensitive to ethics	Relevance & transferability
Lundqvist & Jakobsson [28]	$\checkmark$	$\checkmark$	$\checkmark$	✓	$\checkmark$	$\checkmark$	$\checkmark$	✓	$\checkmark$	$\checkmark$	✓	$\checkmark$
Pohlman [26]	$\checkmark$	$\checkmark$	$\checkmark$	✓	$\checkmark$	$\checkmark$	$\checkmark$	✓	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Lundqvist, et al., [30]	✓	✓	✓	✓	✓	✓	$\checkmark$	✓	✓	√	$\checkmark$	$\checkmark$
Lindberg, et al., [23]	✓	$\checkmark$	×	✓	$\checkmark$	×	$\checkmark$	✓	×	×	$\checkmark$	$\checkmark$
Lindberg, et al., [22]	$\checkmark$	×	×	✓	$\checkmark$	$\checkmark$	×	✓	×	×	$\checkmark$	$\checkmark$
Arockiasamy et al., [24]	✓	$\checkmark$	×	✓	×	$\checkmark$	$\checkmark$	✓	×	$\checkmark$	$\checkmark$	$\checkmark$
Pohlman [27]	✓	<b>√</b>	<b>√</b>	✓	$\checkmark$	$\checkmark$	$\checkmark$	✓	$\checkmark$	$\checkmark$	✓	✓
Hollywood & Hollywood [25]	✓	✓	✓	✓	$\checkmark$	$\checkmark$	$\checkmark$	✓	$\checkmark$	$\checkmark$	✓	✓

<sup>\*</sup>Dixon-Woods et al., [29] 'Fatally Flawed' criteria

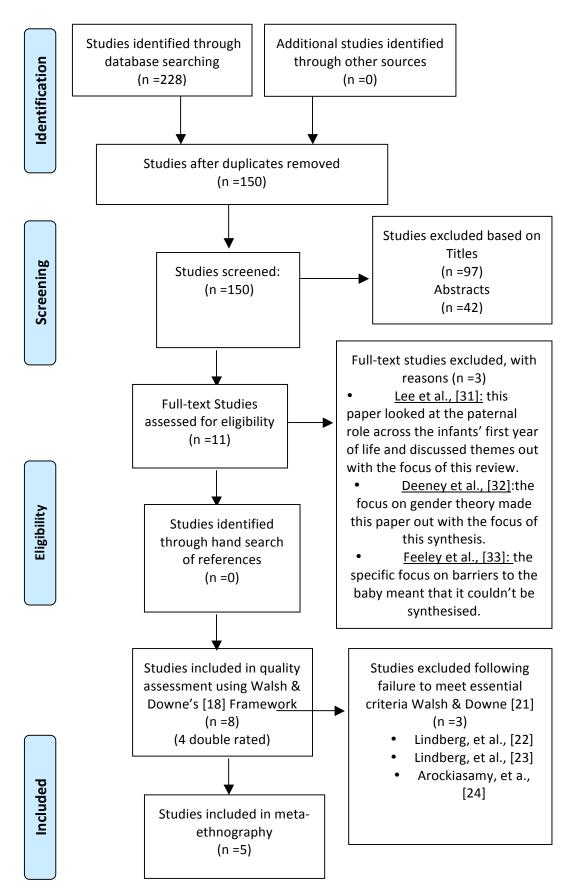


Fig 1. Flowchart of search results

**Table 3**Characteristics and themes from studies included in the synthesis

Study (year)	Country	Method	Participants	Article Themes	3 <sup>rd</sup> Order Themes			
Lundqvist & Jakobsson [28]	Sweden	Content Analysis	8 fathers Aged 27-35 years Infants gestational ages 28-34 weeks All had additional medical complications	Concern	'Anxious preoccupation with mum and baby'			
(2003)				Stress	'Demanding routine'			
				Helplessness	'Sidelined & Helpless'			
				Security	'Empowered by being informed'			
			aside from preterm	Support	'Socio-emotional support'			
			status	Happiness	'Connecting with baby through active contact'			
				Latent: themes control & non-control (This will not be analysed as quotes were not provided)				
*Pohlman [26] (2005)	USA	Interpretive Phenomenological analysis	9 white fathers aged 22-40 years Infants gestational ages 25-32 weeks	(Subordinate themes) Work after birth: a renewed sense of fervour	'Fathering through the workplace'			
				From expert to novice	'Deskilled & helpless'			
				Juggling work and the outside world	'Juggling multiple demands'			
Lundqvist, et al., [30]	Sweden	A Hermeneutic Phenomenological Method	13 fathers aged 27-45 years Infants gestational ages 25-32 weeks	(Feelings of distance) Living beside reality	Living beside reality			
(2007)				Becoming an outsider	'On the sideline'			
				Living with worry	'Worry for mum and baby'			
				(Feelings of proximity)	'Connecting with baby: through facilitated contact and			
				Returning to reality	involvement in caregiving'			
				Becoming a family	'Growing into fatherhood'			
				Facing the future	'Staying positive'			

*Pohlman [27] (2009)	USA		Interpretive Phenomenological analysis	9 white fathers aged 22-40 years Infants gestational ages 25-32 weeks	(Subordinate themes) The emotional costs of fathering in a technologically textured environment	'The need for nurture'
					The power differential between nurses and fathers	'Nurse/father power dynamic'
					Fathering despite the technological imperative	'Connecting with baby'
Hollywood & Hollywood [25]	Dublin, Republic Ireland	of	Phenomenological approach	5 fathers, Infants gestational ages 24-30 weeks	(Effects of hospitalisation)	'Apvioty for baby'
(2011)	ireianu			24-30 Weeks	Anxiety Feelings of helplessness	'Anxiety for baby' Feelings of helplessness
					Fear of the unknown	'Anxiety for baby'
					Realisation of becoming a father to a premature infant	Realisation of becoming a father to a premature infant
					Information sharing: the double edged sword	Information sharing: the double edged sword
					Paternal role vs. Maternal role	'Paternal inequality: sidelined'
					Constraints of work	'Balancing work and fatherhood in the NICU'

<sup>\*</sup>These two papers were based on the same study. As the focus of each differed, and each offered unique insights, both were included in this review.

Table 3 exhibits a list of themes from each of the studies included in the synthesis. Through the process of meta-ethnography, a new interpretation of themes from the individual interpretive accounts was developed.

This process elicited the following six key themes on fathers' experience in the NICU; (1) on the sideline, (2) from disconnected to connected as a father, (3) juggling multiple demands, (4) anxious pre-occupation with mum and baby, (5) socio-emotional support, and (6) information sharing: the double-edged sword. Each theme will be discussed in turn.

Quotations from study participants will be distinguished from those of study authors through the use of italics.

#### 'On the sideline'

Fathers' experiences of being 'on the sideline' were identified across all studies. The fathers' lack of role is reflected in this sports analogy. Lundqvist et al., [30] described fathers feeling "...that they were just standing on the sideline, like a spectator..." [30, pp493]. Fathers felt unable to protect their infant, and outside of the decision making process [28,30]. The inability to play their part contributed to feelings of helplessness [26,28,25]; "You're supposed to look after them..., but then suddenly you just feel totally helpless, you can't do anything, you can't be part of the decisions, you can't be there to discuss...". [28, pp27]. The NICU environment can contribute to fathers' feeling of being 'sidelined' and consequent helplessness, as demonstrated by one father who highlighted the influence of the technological environment; "... felt so helpless because they were in the glass incubator and I couldn't really do anything for them...". [25, pp35]. A power imbalance between fathers and staff also contributed to fathers feeling 'on the sideline', as fathers looked to staff for permission to care for their child [27,30]; ".... It's kind of a strange feeling when she's yours, but you have to ask permission to do things. We weren't sure where the boundaries were and what we should do." [27, pp9]. This power imbalance can prevent fathers expressing their opinions regarding their infant's care; "... we don't push, you know. I don't want to get on the bad side of a nurse that's watching my kid..." [27, pp8].

Fathers may also be sidelined by the female dominated environment, and inequality in their treatment compared to that of mothers [25,27]; "There was never really; "Ok Dad, now it's your turn". The emphasis was always on the mother" [25, pp37]. Separation from mother and baby also contributed to fathers' feelings of being an outsider [25]

#### 'From disconnected to connected as a father'

Fathers experienced an initial sense of disconnection to fatherhood [25,28,30]; "...I probably didn't feel very much, because I didn't really believe it... that could be someone else's kid..." [28, pp27]. This sense of unreality was linked to a lack of accountability for their infant's care. Engagement in caregiving activities, particularly holding their infant for the first time, helped fathers connect to their infant; "the first time each father held his baby seemed to be important for activating his feeling of reality and connection and seemed to initiate transition to fatherhood" [28, pp28]. Direct contact was not the only way that fathers connected with their infants; Pohlman [27] described how fathers in her study overcame the technological barrier of the NICU through using their voices - "...I'll stick my mouth through that [isolette porthole] and "oooh" like that and try to get her used to my vocal cords or whatever...." [27, pp10].

Fathers also sought to care for their baby through taking on the 'breadwinner role'; they returned to work with greater determination and zeal in order to provide for their family [26].

#### 'Juggling multiple demands'

Several studies highlighted the multiple demands which faced fathers during this time [25,26,28]. Fathers were pulled several directions; "... I feel really divided, for [mum]... wants me to be here the whole evening...

But you have to finish the work you are doing first, and then it's a total mess at home, so it feels a bit stressful" [28, pp27].

Working fathers struggled with daily hospital visits, and experienced guilt when work commitments restricted time with their baby [25,26];"... parents that were always there... I'm coming in after work, you know, it kind of puts you on a guilt trip..." [26, pp209-210]

Juggling the demands of work and baby impacted on fathers' performance at work [25,26]; "Yeah that was a big problem for me. Trying to concentrate on running a business when you got something as serious going on is so hard" [25, pp38]. However, work could also offer fathers a helpful distraction [25,26]; "...I think work helps. I think if I wasn't working I would have gone stir crazy. You would be worried about everything. You definitely need to keep occupied. It's therapy." [25, pp38].

Fathers also had to take on greater responsibility for running their homes [26,28]; "...the house maintenance, the laundry, cleaning the house, things like that. There just hasn't been a lot of time to do it." [26, pp210]. The studies conveyed fathers' feelings of guilt at having to juggle these competing demands.

'Anxious pre-occupation with mum and baby'

Several studies highlighted fathers' anxious pre-occupation with mum and baby [25,28,30]. They were concerned for mum, and prioritised her needs [28,30]; "Yes, see to it that the mother is well... I think in the first few days it's more important that the mother feels well" [28, pp27].

Fathers also feared for their babies' survival; "...prayed to every dead relative that I've got, begging them to do something for them" [25, pp35]. This anxiety can remain at discharge, as fathers can feel apprehensive of leaving the security of the NICU behind [28]. Their anxiety was linked to the NICU environment; seeing their infants' dependent on the technological equipment highlighted the seriousness of their situation [25,30]. Fathers watched staff anxiously, hypervigilant to any sign of risk [30]. They were apprehensive of handling their baby for fear of causing harm; "As much as I wanted to... I would be quite nervous of taking them

out and handling them. More so because I don't want to disturb them or put them at risk of infection" [25, pp34-35].

#### 'Socio-emotional support'

Several studies identified fathers' need for 'socio-emotional' support [27,28,30]. Fathers appeared to benefit from talking with others who were, or had been, in similar situations to themselves, and to have their feelings confirmed [28]. One father suggested that this could be achieved through organised groups; " ... you get to talk to other people, and they're in exactly the same, and they have roughly the same feelings. And then you have some professional leader who knows what it's about and can give some answers..." [28, pp28]. Several studies identified staff as being key sources of support [27,28,30]. The development of close, trusting relationships with staff was facilitated by confidence in staff competence, and feeling that they genuinely cared for them and their baby [27,28,30]; "... the nurse out there today, she is a real nice woman. She's really caring about the baby, see who they are and that they are a baby..." [27, pp6]. Consistency in care providers was identified as important; "You get a rapport with somebody and it's hard to switch because you can't just assume you can talk to this person about the same subject and they're going to understand..." [27, pp8].

#### 'Information sharing: the double-edged sword'

Two papers identified the importance of information in alleviating fathers' anxiety [25,28]. Information given in advance of an event that could affect mother and baby helped fathers feel prepared and assured; "...the more things you know before, the less anxious you are, that's obvious" [28, pp28]. Fathers feel greatly advantaged by being introduced to the NICU before admittance. Information provision also helped manage fathers' distress through promoting a supportive relationship with the staff; "I found that nobody was ever too busy to give us time. And often just to give us explanations. That's what we needed" [25, pp36]. How information was

delivered, however, influenced whether it was helpful or not. Fathers want information in a language they can understand; "In Lay Mans terms. You don't really need to know the science behind it" [25, pp36]. Inconsistency in information was identified as a problem for fathers; "...If you asked the same question six different times to six different people you would get six different answers" [25, pp36]. Finally, fathers need information to be given in a way that allows hope; "... you meet Dr. X and I mean you are coming out singing. Dr. X gives you so much hope... but yet realistic... Whereas Dr. Y... feel like slashing your wrists sometimes after talking to Dr. Y" [25, pp36]. Fathers also seek ways to inform themselves independently from staff, for example through watching and reading the monitors [28]

#### Discussion

The following six themes were derived from the synthesis of five qualitative studies on fathers' experiences in the NICU: 1) on the sideline, 2) from disconnected to connected as a father, 3) juggling multiple demands, 4) anxious pre-occupation with mum and baby, 5) socioemotional support, and 6) information sharing: the double-edged sword. The implications of these themes for fathers' support needs will now be considered in relation to the existing constructs of support outlined in the conceptual NPSM [8].

Fathers' feelings of being 'sidelined' by an inability to play an equal part in their infant's care highlights their need for **parental esteem support** (i.e. actions that respect, enhance, and support the parental role). This would involve staff working collaboratively with fathers; including them in decision-making and facilitating their involvement in their infant's care. In addition, the provision of private family rooms and the opportunity for overnight stays would support fathers' involvement in the NICU. These provisions have been found to enhance fathers' sense of security in this setting [23,34]. Such provisions, however, are not included within the existing NPSM, but are within the original construct of 'instrumental support' as defined by House [9] (i.e. assistance of any kind including

financial, time, labour, or *environmental modifications*). This suggests that the construct of **instrumental support** (which would **include** the 'caregiving' construct of the NPSM) may be valid for fathers in the NICU.

Fathers' sense of unreality around their new role, and a disconnection to their newborn baby is well reported in literature [13,35]. This is understandable as an infant's premature arrival reduces parents' time to emotionally and psychologically prepare for their new role [36]. Further, the infant's presentation, the technological environment and the power imbalance between father and staff can serve as a barrier between father and baby [33]. Such barriers prevent fathers from taking immediate responsibility over their child, which this review suggests may prolong feelings of unreality and disconnection. However, contact with their baby, through holding and caregiving, facilitated connection. This is widely supported by literature linking involvement in infants' care to attachment [33,37,38]. Therefore, father-infant attachment could be assisted through parental esteem support in the form of facilitated physical contact. Fathers' efforts to overcome physical obstacles, and connect with their infants through speech, has been identified elsewhere in the literature [33]. This indicates a way by which staff can support and encourage fathers' involvement when physical contact is not possible.

Further, returning to work was identified as a way for fathers to feel they are caring for their infant, therefore it is important for this role to be acknowledged and supported where appropriate. This encouragement and support, in addition to the collaborative working practices detailed above, may also minimise the perceived power imbalance between fathers and nurses.

Fathers in the reviewed studies faced multiple demands. They had to juggle hospital visits with work and had increased responsibility for running the home. This finding is supported by other literature in this area, as is the finding of the strain such demands place [24,32,33]. Fathers felt inadequate and guilty as their responsibilities took them away from the

NICU and were conscious of their reduced effectiveness in work due to the multiple demands placed on them. However, work also offered fathers a welcome distraction, and a feeling of purpose. Therefore flexible parental leave, such as the soon to be implemented UK governments 'reform of flexible parental leave', which will allow parents to choose how they share parental leave in the first year, are required to enable fathers to manage their competing demands, and to be present and involved in their infants care. **Informational support**, in the form of advice on how fathers could avail themselves of their leave rights could also support fathers in managing their competing demands.

Consistent with other research [39] this review found increased levels of anxiety among fathers in the NICU, which highlights their need for access to informal and formal (e.g. psychological services) emotional support (e.g. listening, caring behaviours, and concern to help parents cope). The technological environment of the NICU was identified as contributing to fathers' anxiety around their infant's outcome- a finding supported within the wider literature [32]. Fathers' apprehension in handling their fragile infants may also be related to the surrounding medical technology [33]. Therefore informational support (i.e. supportive communication and provision of information about the child and parent rights) in the form of increasing fathers' familiarity with the medical technology is needed to reduce fathers' anxiety and facilitate their involvement in their child's care [33]. Consistent with Jackson et al., [13] this review found that fathers are nervous of discharge. Therefore, they may require additional parental esteem support (e.g. increased autonomy in caring for their infant) to prepare them for leaving, as well as access to post NICU support.

Fathers' need for caregiving support (i.e. the provision of high quality care to the child) was highlighted by this review's finding that fathers watch staff anxiously for signs of risk to their baby. Confidence in staff competence can alleviate fathers' anxiety and enable them to entrust their infant's care to staff [13], and a calm demeanour and body language can support fathers' feeling of security [34]. Further, as fathers were found to prioritise

the mothers' wellbeing (a finding supported in the wider literature [34,31]), caregiving support (as part of **instrumental support**) may need to be extended to include mothers.

Fathers sought opportunities to speak with other parents who are going through, or have gone through the same experience to have their feelings confirmed, for example, through organised groups. Consistent with research on mothers [40], this review also identified that a supportive relationship with staff is a particularly important source of support for fathers. This review found that such relationships are fostered through the availability of consistent care providers, who demonstrate genuine care for both the father and infant's wellbeing. These findings confirm that emotional support from staff, as outlined in the NPSM, is important for fathers to form supportive relationships with staff. Further, these findings indicate the importance of social support for fathers in the NICU. Social support is not included within the existing NPSM, but is indicated in the original definition of the construct of 'esteem support' as defined by House [9] (i.e. the provision of affirmation, feedback and social companionship). This suggests that it may be helpful to include social support into the NPSM's definition of parental esteem support for fathers in the NICU.

Informational support was found to alleviate fathers' anxiety, and to foster trusting relationships with staff. Information sharing may reduce fathers' anxiety through empowering them and increasing their sense of control [23,24]. For information to be supportive, however, it must be shared sensitively; this relates to when and how it is provided. Information given in advance helps fathers feel prepared, however as fathers may struggle to retain such information the first few days, it should be shared repeatedly, and backed-up in written form [23]. Fathers also need information to be communicated simply and consistently, as technical jargon can increase fathers' apprehension in handling their baby [32,33]. Lastly, while fathers want realistic information, they need to receive it in a manner that fosters hope.

#### Reflexivity

While completing this review, the author worked in a NICU, and conducted research into the lived experiences of fathers with infants cared for in a NICU. It is inevitable that these experiences will have influenced the author's interpretations.

#### Limitations

This review was restricted to published journal articles, which may have produced a truncation bias, as the full details of qualitative research may not have been available due to the word restrictions on published work. The profile of strengths and weaknesses may therefore reflect the quality of the written report as opposed to the study itself [41]. Furthermore, the decision to exclude papers on the basis of quality assessment means that relevant data from the excluded papers may have been missed [42]. However, this decision was balanced against safeguarding the integrity of this meta-synthesis [21]. Finally, as with primary qualitative research, translations will have been influenced by the authors' own values and theoretical influences, and as such will be one of several possible ways of interpreting the collection of studies.

#### Conclusion

Support needs identified from the findings of this review indicate that the constructs of support outlined within the conceptual NPSM [8] are relevant for fathers of infants in the NICU. The NPSM therefore appears to be a relevant model of support for this population.

Additional support needs were identified which did not fall within the existing NPSM, specifically: social support, access to flexible parental leave, private family rooms, and 24 hour access to the NICU. These additional support needs could however be accommodated within the NPSM; consistent with House's [9] definitions of support, social support

could be incorporated into the construct of **parental esteem support**, and environmental adaptations and financial support could be included, along with good quality caregiving, under the construct of **instrumental support**.

These findings indicate how this revised NPSM could be implemented in clinical practice to inform FCC and thereby promote parent and infant wellbeing

#### **Further Directions**

The exclusion of three papers following quality assessment highlights the need for more high quality research in this area. Further, the findings from this review were based on studies conducted in just three countries, therefore wider research across different countries is required before generalising these findings across different nations with their varying cultures and disparate health care systems.

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### **Chapter 2: Major Research Project**

A Qualitative Study of Fathers' Experiences of a Scottish Neonatal Intensive Care Unit

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#### **Plain English Summary**

<u>Background:</u> Heightened distress levels among parents of infants hospitalised in a Neonatal Intensive Care Unit (NICU) and the promotion of Family Centred Care (FCC) (a philosophy of care intended to assist families with hospitalised children), emphasise the requirement for health care professionals to understand parents' support needs.

Most of what we know about parents' needs in the NICU has come from research focusing on mothers. Research comparing mothers' and fathers' experiences in the NICU, however, indicates that mothers' and fathers' needs differ in important ways. The available research, therefore, does not provide a sufficient basis from which to accurately understand fathers' needs.

While, to the best of the author's knowledge, no current model of parental support needs is used in practice in NICUs, the Nurse Parent Support Model (NPSM) offers a potentially useful model for understanding parents' support needs. As part of the current research, findings from qualitative studies (a research approach which gathers information that is not in numerical form) that have explored fathers' experiences in the NICU were reviewed and brought together with the aim of clarifying fathers' support needs. This review indicated that the items of support outlined within the NPSM (i.e. 'informational support', 'emotional support', 'parental esteem support', and 'caregiving support') are relevant for fathers of infants in the NICU, and suggested how the existing model could be modified to incorporate additional forms of support.

Findings from the review, however, were based on studies conducted in just three countries, with important differences emerging from studies with different countries of origin. Therefore, before findings can be generalised, and inform FCC, further qualitative research, across different countries,

was required to gain an in-depth understanding of fathers' experiences and support needs.

Objectives: 1) To gain an in-depth understanding of fathers' experiences of having their preterm infant hospitalised in a Scottish NICU, and 2) to develop a clearer understanding of fathers' support needs.

<u>Methods:</u> Six fathers of infants cared for in a Scottish NICU completed semi-structured interviews about their experiences. Interpretative Phenomenological Analysis (a type of qualitative analysis) was used to identify themes emerging from these interviews.

<u>Results:</u> Six broad themes were identified: 1) adjusting to the demands of the situation, 2) relationships with staff, 3) technology: a divided opinion, 4) becoming a father, 5) emotional reactions, and 6) adaptive responses.

Conclusion: This study offers an in-depth understanding of fathers' experiences of having their preterm infant cared for in a Scottish NICU, and has helped to develop a clearer understanding of fathers' support needs. Findings: 1) validate the relevance of the items of support outlined within the NPSM for fathers in the NICU, (2) justify changes to the existing model to incorporate additional forms of support which are not currently included (e.g. social support and the provision of overnight accommodation), and (3) indicate how this revised model could be implemented in clinical practice to inform the provision of FCC and thus promote parent and infant wellbeing.

#### Abstract

Objectives: 1) To gain an in-depth understanding of fathers' experiences of having their preterm infant hospitalised in a Scottish Neonatal Intensive Care Unit, and 2) to develop a clearer understanding of fathers' support needs.

Methods: Six fathers of infants cared for in a Scottish Neonatal Intensive Care Unit completed semi-structured interviews about their experiences. Interpretative Phenomenological Analysis was used to identify themes emerging from these interviews.

Results: Six overarching themes were identified: 1) adjusting to the demands of the situation, 2) relationships with staff, 3) technology: a divided opinion, 4) becoming a father, 5) emotional reactions, and 6) adaptive responses.

<u>Conclusion:</u> This study offers an in-depth understanding of fathers' experiences of having their preterm infant cared for in a Scottish Neonatal Intensive Care Unit, and has helped to develop a clearer understanding of fathers' support needs.

Findings: (1) validate the relevance of the constructs of support outlined within an existing conceptual model of parents' support needs (the Nurse Parent Support Model) for fathers in the NICU, (2) justify modifications to the existing model to incorporate additional forms of support which are not currently included, and (3) indicate how this revised model could be implemented in clinical practice to inform the provision of Family Centred Care and thus promote parent and infant wellbeing.

<u>Keywords:</u> Fathers' experience, Neonatal Intensive Care Unit, NICU, Preterm infants, Qualitative research

#### Introduction

Parents of infants admitted to a Neonatal Intensive Care Unit (NICU) experience symptoms such as anxiety, depression, and feelings of powerlessness, hopelessness and alienation [1]. This distress has been associated with detrimental effects on child development and family wellbeing [2,3].

Family Centred Care (FCC) is "a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognised as care recipients" [4, pp1318]. In the neonatal unit, FCC aims to help parents manage their anxiety and altered parenting roles [5], and it has been found to be effective in reducing stress for both parents [6] and infants [7]. To provide effective FCC, and thus promote parent and infant wellbeing, NICU health professionals require a thorough understanding of parents' needs.

Most of what we know about parents' needs in the NICU is informed by research on mothers. The only published review of parents' needs in the NICU [8] utilised studies which focused on mothers' experiences exclusively, or on parents' experiences simultaneously, often including a much higher percentage of mothers. Research comparing mothers' and fathers' experiences in the NICU, however, indicates that these differ in important ways. For instance, mothers' stress levels have been shown to lessen between birth and discharge, while those of fathers increase [9]. Fathers appear to experience greater stress in relation to managing their, often increased, responsibilities outside the NICU [10]. Mothers want increased responsibility for caring for their infant, while fathers want a balance between work and family life [11]. Therefore, the available research does not provide a sufficient basis for accurately understanding fathers' needs.

In recent years a small number of qualitative studies have been published that have looked into fathers' experience of the NICU. Several of these studies have indicated that fathers in the NICU experience feelings of anxiety for their partner and infant [12,13,14,15,16], helplessness [17,14,16,18], and an initial sense of unreality and disconnection to fatherhood [12,14,15,16,19]. A number of studies suggest that fathers also experience a power imbalance between themselves and staff [2,19,20], and feel sidelined by an inability to play an equal part in their infants' care [14,15,16,20,18]. Numerous studies also identified that fathers are faced with multiple demands during this time, which can act as a barrier to their involvement in the NICU [14,16,18, 21].

The emerging body of qualitative literature in this area indicates a number of ways in which fathers could be supported during this difficult time. For example, several intimate that fathers could be supported by sensitively and simply shared information [12,14,16,21] and by social and emotional support from other parents and staff in the unit [12,15,20,21]. Fathers' relationships with staff could be enhanced by confidence in staff competence, and through feeling that staff genuinely cared [14,15,20]. Finally, several studies suggest that fathers' initial sense of disconnection to fatherhood could be overcome by the opportunity to hold, and be involved in their infants care [14,15].

However, when screened using a qualitative quality assessment tool [22], a large proportion of the existing research does not meet quality criteria [12,13,17,19]. In particular, papers failed to explicitly state their qualitative approach (which means that the reader cannot know if the approach is consistent with the research intent), and to adequately evidence that the subjective meanings of participants were portrayed in the interpretations given. This highlights the need for further high quality qualitative research in this area.

As part of the current research an Interpretive Synthesis of qualitative studies that explored fathers' experiences in the NICU was completed with

the aim of clarifying fathers' support needs [23]. To the best of the author's knowledge, no model of parental support needs is currently used in practice in NICUs, however findings from the Synthesis [23] indicated that the constructs of support outlined within the Nurse Parent Support Model (NPSM) [24] are relevant for fathers of infants in the NICU. The NPSM is a conceptual model, which was developed to underpin the Nurse Parent Support Tool (NPST; an assessment tool designed to measure parents' opinions of nursing support during their child's hospitalisation in paediatric and neonatal settings). As such there is, as yet, no direct research into the validity of this model, although there is strong support for the content validity of the NPST. Specifically, the measures taken in developing the tool (e.g. the use of a conceptual framework and data from interviews with parents of hospitalised children, generating items from the literature, and pilot testing with experts and parents [24].

The NPSM is based on House's conceptual definitions of social support [25] and considers the provision of support during a child's hospitalisation as being critical for both the parent and child's coping ability. It outlines four types of support as being especially important to meet the needs of parents of hospitalised children: 'informational support', 'emotional support', 'parental esteem support', and 'caregiving support'.

Informational support includes supportive communication and the ongoing sharing of information to parents. Emotional support includes listening, caring behaviours, and being concerned in ways that help parents cope with the illness and other aspects of their lives. The NPSM re-conceptualised House's construct of 'esteem support' [25] as 'parental esteem support'; reinforcing, and supporting the parental role. Similarly, House's construct of 'instrumental support' [25] was re-conceptualised as 'caregiving support'; good quality care giving for the child.

The Synthesis [23] identified several support needs that were **not** included in the existing NPSM:- **social support**, **access to**, **and advice in respect of**, **flexible parental leave**, **private family rooms**, **and 24 hour access** 

to the NICU. It was therefore suggested that, consistent with House's [25] original definitions of support, social support be incorporated into the construct of 'parental esteem support', and environmental adaptations and financial support be included (along with good quality 'caregiving support') under the construct of 'instrumental support' (any type of assistance, including financial, time, labour, or environmental modifications).

Findings from the Synthesis, however, were based on studies conducted in just three countries. Therefore, further research is required before findings can be generalised, particularly as important differences have emerged from studies with different countries of origin. For example, fathers in a qualitative US based study [18] wished to return to work and provide financially for their infant, while those in a Swedish study [15] wanted to be present and actively involved in their infants' care. Fathers in a Canadian based study [17] maintained a sense of control through increased activity away from the NICU, while fathers in another Swedish study [26] felt more in control when together with their infant in the NICU. These differences may reflect countries' differing health care systems, paternity leave provisions, and cultural beliefs and attitudes around fatherhood.

Therefore, to determine whether the findings of the Synthesis can be generalised, and identify an effective model of support for fathers of preterm infants cared for in the NICU, more high quality qualitative research, conducted across different countries, is required to gain an indepth, bottom-up understanding of fathers' experiences and support needs.

### **Aims**

- 1) To gain an in-depth understanding of fathers' experiences of having their preterm infant hospitalised in a Scottish NICU.
- 2) To develop a clearer understanding of fathers' support needs.

## Method

# **Participants**

Six fathers consented to participate in interviews around their experience. This number is suitable for Doctorate level research employing Interpretative Phenomenological Analysis (IPA); it enabled data saturation and allowed for a detailed interpretive account of each interview [27]. Participant details are presented in Table 1 (numerical identifiers have been used to protect anonymity).

**Table 1** Participant information

	Age	Marital status	Religion	Employment	Gestation age of baby (weeks)	Length of stay (week)	No. of other children
F1	20	Engaged	None	Unemployed	23	18	0
F2	35	Married	None	Driver	28	14	0
F3	28	Married	Church of Scot.	Music teacher	32	4	0
F4	46	Married	Atheist	Self employed	32	3	2
F5	29	Engaged	None	Armed Forces	25	15	0
F6	32	Married	Catholic	Driver	32	5	0

#### Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were selected to preserve a homogeneous sample. English speaking fathers of infants born ≤32 weeks gestation and cared for in a Scottish NICU were included in this study. Consistent with previous research [28], fathers below the age of 18, and fathers of multiple births above twins, were excluded from this study as they are considered to present with unique experiences. Fathers of infants who died, or were terminally ill were excluded for the same reason.

#### Recruitment Procedures

Fathers were recruited from a convenience sample of parents of infants in a West of Scotland NICU between December 2013 and February 2014. Fathers with infants nearing discharge were approached by Nurses with 'Good Clinical Practice for Researchers Training' and provided with an information sheet (See Appendix 5). Fathers who provided written consent (See Appendix 6) via free postal return were contacted by phone by the Principle Investigator (PI: a female Trainee Clinical Psychologist) and invited to participate in interviews about their experiences in the NICU. Interviews were offered to fathers at a time convenient to them.

#### Research Procedures

Following informed consent, non-directive semi-structured interviews were conducted with the PI in private hospital rooms. Interviews were chosen to allow fathers to share detailed accounts of their experiences, and their thoughts and feelings about them [27]. An interview schedule based on the NPSM model and discussion with NICU staff teams (see appendix 7) was employed to facilitate the discussion of relevant topics [27]. The

schedule was brief, and minimum direction was provided to allow fathers to tell their stories, in their own words, in as much detail as possible.

All interviews began with an informal chat designed to put fathers at ease and build a rapport. Demographic information (Table 1) was gathered before moving onto more sensitive topics. Frequent summaries allowed fathers to correct misconceptions and opened up topics for discussion. Interviews lasted between 55-86 minutes and were brought to a close with a more neutral discussion. Interviews were recorded and transcribed verbatim, identifiers were removed and transcripts were given numerical identifiers.

# Design

Interpretative Phenomenological Analysis (IPA) was employed in this retrospective study. IPA is a qualitative research approach theoretically underpinned by phenomenology, hermeneutics and idiography [27], and was chosen because it is concerned with the detailed evaluation of lived experiences, the meaning of them, and how they are made sense of [29].

## Researcher Reflexivity

Prior to, and during, data collection the PI worked in a NICU providing psychological support to families, and also completed an Interpretive Synthesis of research in this field. This work provided insight into parents' experience within the NICU, and may have generated 'pre-understandings'. These were reflected on within research supervision.

# Data Analysis

Transcripts were analysed by hand following the six-step heuristic framework outlined by Smith et al., [27] (See appendix 8). The author immersed herself in each father's narrative through reading and re-reading each transcript. Line-by-line initial noting identified points of significance,

from which emergent themes were identified (See appendix 9 for a sample extract of this process). Emergent themes were compared and clustered into super and sub-ordinate themes (See appendix 10). These were then compared and integrated across interviews to generate a final list of themes (See appendix 11). In line with the IPA Quality and Evaluation Guide [29], to ensure sufficient sampling from each corpus to show density of evidence for each theme, extracts from at least 3 participants were required for each theme. Similarities and discrepancies were considered in terms of fathers' individual circumstances and the context of the unit (See Appendix 12).

Several steps were taken to ensure rigour and transparency. A journal was kept to record and justify key decisions, and field notes were made for each interview. The research team independently re-analysed two transcripts and discussed all emergent themes as a means of audit. The IPA Quality and Evaluation Guide [29] was followed, and each stage of this project was compared against a qualitative quality assessment framework [22]. Finally, in line with these guidelines, verbatim quotes are provided to prove sufficient sampling from transcripts.

## Ethical Approval

The University of Glasgow, West of Scotland Research Ethics Committee (Appendix 13), and Ayrshire and Arran Research and Development team (Appendix 14) approved this study.

#### Results

Six overarching themes were identified: 1) adjusting to the demands of the situation, 2) relationships with staff, 3) technology: a divided opinion, 4) becoming a father, 5) emotional reactions, and 6) adaptive responses. (See Appendix 11 for a table of themes and their main dimensions.)

Quotations are provided to illustrate and support each theme. For clarity, participant quotations are presented in italics, with pauses in their speech

indicated by a series of three dots. Communications from the author are in parenthesis.

## Adjusting to the demands of the situation

This situation placed a number of demands on fathers, which required them to make significant adjustments. Consequently, a number of subthemes were identified: the daily grind, being there for mum, and juggling work and the NICU.

'The Daily Grind'

All fathers spoke of the strain the repetitive daily routine placed on them, and of their lives as being on hold;

"we were actually here every single day and it was draining us we were we were sleeping in here... it was just, it was a nightmare,... we were here from 11 till say 11 until 11 at night" (F1)

'Juggling work and the NICU'

All but one of the employed fathers reflected on the demands of juggling work and the NICU. As one father put it; "I had to go back to work. That was mental" (F2). Another father worked away from home and spoke of the costs this entailed for him emotionally, physically, financially, and also on his ability to be there for, and connect to, his infant;

""I think because of the amount of time I have spent away as well I don't feel that I have bonded 100% as well, so I think in a way I have had a bit of bonding issues ..."

"...being 450 miles away annoys the h\*ll out of me when like I am like missing the first part sort of thing, sort of annoys me but at the end of the day I just got to deal with it, but....(Sounds like that has been really hard to manage that distance and....) Oh yes and like financially it's has been

crippling, the first month or two, nightmare. Emotionally yes, it sort of did shock me a bit and I think just physically draining, like there's countless times where, well how I haven't crashed driving up that motorway I do not know..." (F5)

Another father spoke of the impact juggling work and the NICU had on his performance at work;

"Well I could be sat in a two hour meeting and I could feel myself going like that [mimicked nodding off], and have to right just think of something to say for the sake of saying it and keep myself awake you know half the time as well, because I didn't want to feel unprofessional and fall asleep in the middle of a meeting. Especially if I am hosting the meeting!" (F4)

All fathers in employment discussed paternity leave. Three described the distress caused by trouble accessing it. In particular one self-employed father regretted that he could not afford it;

"...I can't afford to take a lot of time off because it affects my own kind of finances. (And you would you have liked to?) I would have liked there to have been some sort of mechanism for me to have paternal leave as a self employed person" (F4)

Three fathers, however, identified that the availability of good paternity leave was a great source of support;

"I think I am just lucky because the [employers] are really good when it comes to compassionate issues and they have given me like 4, 5, 6... 8 weeks off, to deal with it all..." (F5)

'Being there for Mum'

Fathers spoke of the importance of being there for their partners, and their suffering when separated from them at the end of the day;

"...then I had to go home. I think that was one of the worst bits ..." (F6)

Fathers felt distressed when having to choose between being with their baby and their partner in the hospital;

"I remember they said oh dad you can come over and I didn't want to leave [wife]" (F3)

The majority of fathers saw it as their role to look after mum;

"...I thought he [son] doesn't need me to drain down on him as well because there will be no one watching over her... he was ill, he has got doctors and nurses for that, he can deal with that, whereas like, yes, [partner's] got herself, she has got me to look after her." (F5)

Fathers prioritised mum's wellbeing and adopted the role of the strong protector;

"... it just felt like if I just hold it together and get through it at least [wife] can be the one that's kind of emotional! (Yes.) I was still emotional but it just felt like I had to kind of stay strong for her." (F6)

For several fathers, this included taking on the difficult task of managing the wider families involvement, particularly grandparents. Fathers negotiated visiting times and 'safe' topics for discussion in order to protect their partner;

"you feel as you are being the big bad boy by going and saying no you're not...and it sounds wrong to say but... (A difficult position to be in?) A horrible position to be in..." (F2)

## Relationships with staff

Every father reflected on their relationship with staff, resulting in a number of subthemes: the balance of power, fragile trust, identifying allies, and communication.

## 'The balance of power'

All fathers described a changing power dynamic between themselves and staff. Initially they felt uncertain of their rights and deferred to staff, however, gradually the balance of power shifted, and fathers became increasingly assertive and involved in their infant's care. The following two quotes from the same father illustrates this process;

"it's basically that, you are dying to touch him and it's like having a new toy and not being able to touch it as a wee child isn't it... it's weird because you're almost just getting a wee shot of him, how did we used to explain this, neonatal were totally in control of [baby] when he was here we just got a wee shot of him that's generally the easiest way to describe it, the only decisions we ever made on [baby] when he was here is what you put him... in what you dress him."

"... Maybe as you get further down the line it becomes better. But then you just ask the nurses and they tell you. It's not top secret. Because you're entitled to know." (F2)

## 'Fragile trust'

Several fathers' stories conveyed the fragility of their trust in staff, particularly around the monitoring of their infants. Fathers feared that staff could miss things and felt they had to double check;

"one of the numbers went down and I went up to the desk and they were like we have got it all in front of us..." (F6)

Another father was suspicious that parents were not being fully informed;

"I know that maybe deep down they will know how well he is doing but they obviously don't want to tell you..." (F3)

'Identifying allies'

All fathers talked of forming preferences for certain staff that they felt they could trust to care for their baby;

"you just get to know, like a couple that you want, that you want over him because like some, you know that they will watch him like a hawk and they will do everything like above and beyond..." (F5)

Fathers favoured staff that they knew, could joke with, and felt genuinely cared for them and their baby. This was captured by one father's description of returning to their hospital following being transferred to another for specialist treatment;

"It didn't help that we didn't know anybody, any of the doctors or anything up there... when we came back down here it was a big relief because it was back to, it was like a big family back here it was, it was great and when we came back the nurses were amazing with her. (What did they do, what made you feel...?) Well first of all I made my experience a wee bit easier here by joking around with the nurses and they were joking around with me... Well in [another hospital] they don't care about the parents, they don't. The parents can go away, they don't care. (You didn't feel cared about?)

They only care about the babies, the baby's health. Whereas down here they care about the babies and they try their best to make the parents' life easier going through it, which is something I really value, it is." (F1)

Small actions from staff made fathers feel that they really cared;

"Just little things you notice when they write in your diary and you know, just little things they would do which really helps... little small things because you know what they say the smallest things are the biggest" (F2)

#### 'Communication'

A number of communication preferences were identified; firstly, information directly from consultants was judged more reliable, and increased fathers' sense of control over their infant's care:

"you get a better opinion from a consultant than you do from a nurse, because the nurse is just looking after the baby, whereas the consultant, they prescribe medicines and they decide what happens, they have the final say, so having the opportunity to ask what their plans were for [baby] just felt good because we felt as if we could have a wee bit control over what was going on and just felt like not only that we can get control it feels like we are part of their decision and we can find out before the nurses found out what was happening with her, so....!" (F1)

Secondly, fathers wanted information to be shared directly, using simple language;

"You're like just tell me and don't beat about the bush sort of thing, but even just asking, because it was reference his bleed on the brain, they were going through all this blinking jargon and you just ask them to break it down into absolute simple stupid mans terms and they will" (F5)

Thirdly, another father highlighted the need for consistency in information sharing;

"you are not getting told wrong information, but you are getting told different bits and pieces about the same thing so you are trying to put the jigsaw together... it probably does affect you a wee bit because you are sitting going oh what's going on what's happening here" (F3)

Finally, a number of fathers reflected on the need for hope when being given information. One suggested;

"when they break news, maybe give a little bit of hope?" (F5)

# Technology: Split reactions

The technological environment evoked strong emotional reactions from all fathers. However, fathers' views of the machines as helpful or unhelpful were divided. For several fathers, monitors were distracting and anxiety provoking;

"... you get fixated on the machines and you start reading every number! And you think it is dropping down and you think 'why is that dropping down?!" (F6)

However, when asked what it was like seeing his baby in the technological environment, his answer illustrated fathers' split reactions;

"It was...it was a relief knowing they were...he was in the best place" (F6)

Most fathers shared this sense of reassurance as machines provided them with a way to check on their infants;

"... so I knew what was happening with the machines and because I knew what was happening I could keep an eye on, like, my daughter, and because I could keep an eye on her, it was a lot easier." (F1)

# Becoming a father

None of the first time fathers in this study described immediately connecting to their baby or to fatherhood. Analysis suggested that becoming a father was a process facilitated by contact and participation. As such the following subthemes were identified: initial disconnection, and connecting through contact.

'Initial disconnection'

Analysis identified a number of barriers to connection; firstly, being unable to take ownership of their baby;

"it felt like, not like he was a pet but he wasn't fully yours yet because you would have to leave him at the end of the day..." (F3)

Secondly, fathers' inability to hold their infant and engage in typical parenting behaviours prevented several from identifying themselves as fathers:

"No, I am being honest here, I didn't actually feel like a proper dad until I properly held her" (F1)

"people would say you're parents that's great you love being a mum or a dad and you feel a little bit like a fraud you are not really a dad yet because you are not doing the sleepless nights you are not doing the smelly nappies and stuff..." (F2)

Finally, the baby's fragility was identified as a barrier to bonding, as one father said;

"Well because he was so small and fragile I didn't really feel close in a way" (F5).

'Connecting through contact'

All first time fathers associated holding their infant for the first time with bonding. A powerful example of this came from one father who described how he overcame his initial struggle to bond with his baby;

"I picked him up and literally lay on the bed with him on my chest and that's it, bang gone to sleep, and not an issue, just literally held on to my chest sort of thing, digging his little nails in... and I thought nah that's it now, that's done." (F5)

Several fathers identified that active involvement in their babies care was important for them to connect to their new role;

"doing the simplest things like changing nappies or helping nurses out, makes you feel like a parent, it does, whereas if you just sit there and let them do it, let them work away or whatever, it doesn't make you feel like a parent" (F1)

Several fathers, however, spoke of being apprehensive of contact with their baby for fear of causing harm, as illustrated by the following quote;

"I was scared, I had him on skin to skin but I didn't want to touch him because his skin was so thin it was just flaking away" (F5)

## Emotional reactions

This situation evoked a wide-range of emotions for fathers; consequently a number of sub themes were identified: anxiety for baby, ups and downs, frustration, and shock.

'Anxiety for baby'

Understandably, most fathers expressed anxiety around their infant's wellbeing. Fathers were anxious for their baby's immediate safety, and about the possibility of future difficulties;

"the first two days are the hardest because they have got a lot to overcome in those two days" (F1)

"I remember at that point thinking geez, this is quite serious because it could be the case that he is going to have difficulties because he is so early" (F3)

'Ups and downs'

Many fathers spoke of their time in the unit as "like a rollercoaster..." (F1). Fathers linked their fluctuating emotional experience to their baby's progress, in particular moving forward and backwards between rooms;

"we were in that room in special care for about a week and then he had a really bad turn, he really wasn't breathing, he turned blue, oh Jinx and he had to go back to high dependency on Vapofen right up to the high amount and....it was a massive step... was a massive step back and we were like jinx this is back to the beginning..." (F2)

# 'Frustration'

Several fathers experienced frustration. A common source of this was feeling stuck in the unit, particularly as they reached the end of their journey;

"and we thought he is coming home on oxygen can we not just get him home, because we wanted him home, we just wanted him to take him home and we are stuck in there and you felt to yourself you can't do anything with him you are stuck to an oxygen... you are stuck to the wall..." (F2)

Special Care is the final unit before going home, analysis identified that fathers' patience wore thin at this stage;

"when you settle into Special Care that's when it is like right this is, the days grind by and then you are like that's another week down, that's another week and you are not getting anywhere..." (F6)

'Shock'

Fathers' reflections on their first few days conveyed their initial shock. A number of fathers described this time as being "a bit of a blur" (F5), and reported feeling disconnected and numb;

"I was still just... nothing... I can't remember feeling happy, sad, nothing" (F6)

One father described being confused and unable to take in information;

"I said to her [nurse] a couple of days after you told me loads but I don't remember a single thing I was just dazed." (F2)

## Adaptive responses

A number of adaptive responses were identified in analysis; each formed separate subthemes: self-protection, problem focused coping, and social strategies.

'Self-protection'

Fathers reported a number of self-protective strategies; firstly, all fathers described striving to remain hopeful through tracking signs of their infant's progress;

"so every time something happened, a feeding tube was out or she had taken a cup of milk instead of like through feeding tube and stuff like that it was always like one little step closer to coming home" (F4)

Secondly, relinquishing control was a strategy employed especially by those whose work limited their time in the unit;

"I have got people dealing with it, doctors are dealing with it, and what happens I will deal with it later, so I thought... that's not a problem" (F5)

Thirdly, the same fathers described emotionally shutting off from the situation;

"I was like, do I really want to get too attached in the next couple of days, because I thought if I get too attached then it might all fall apart and then he could just bleed to death and stuff later on, so I thought I am not going to get too attached in the next few days, just see how it goes" (F5)

Finally, a number of fathers described not looking too far ahead. They feared getting their hopes up and risking disappointment;

"...just take it one day at a time and that is, because if you do think this time next week, you get too far ahead of yourself so if you just...one day at a time is the biggest thing, to just kind of take wee steps..." (F6)

## 'Problem focused coping'

This refers to actively taking steps to alleviate distress. Two problem focused coping approaches were identified; firstly, seeking information independently; i.e. not relying directly on asking staff. Fathers sought information and guidance through watching their surroundings. Common sources of information were staff actions and machines:

"to start with it was watching the monitors, that was the constant thing with me, every time it went down and then when you get that out your head, you would just watch, you would watch them [nurses] feeding him, watch them changing his nappy, doing his cares, how they turned him and how they done even like the auxiliaries, how they made his bed like made the wee nest and things and you would watch them ....Yes you felt at home quite quickly it was good." (F6)

Secondly, active coping was described; i.e. fathers created a place for themselves through seeking involvement;

"at the start you feel like a bit of a spare part and you are sitting there but they try and get you involved as much as they can and to the extent where I was trying to do as much as I could, and I suppose you have got to the take that opportunity" (F3)

'Social strategies'

Analysis identified two distinct social strategies used by fathers in this study. Firstly, every father described taking comfort from 'social comparisons';

"I could see there were other babies in there who weren't maybe faring quite as well as [my baby], maybe taking a bit longer to come along whereas [my baby] every day something was happening there was a tube out or a mask off or you know the O2 kind of levels all this stuff you could see it was improving on a day to day basis or she was taking more feeds you know because I'd read the charts" (F4)

When fathers compared themselves to parents of full-term infants, however, this strategy could make them feel worse;

"you used to see folk walking in in the morning pregnant and then at night they would walk out with a carrier with their baby and you'd think how can that not be us?" (F6)

Secondly, several fathers valued 'matched social support'; i.e. talking with others who have had, or are having, similar experiences. This helped fathers feel understood;

"see when you talk to someone whose actually done it or been there it means a lot more to you than someone who hasn't because they don't know what it's like..." (F2)

This father coined the phrase 'neonatal buddy' and suggested that the unit "could maybe introduce two couples that's baby matched up...?"

However, for the initial 4-5 weeks fathers appeared to prefer to focus on their own baby. Fathers whose stay extended beyond this timeframe were more likely to appreciate social support;

"... it's a good thing talking to the parents and yes you get some parents who will just sit there and not speak to you and just eyes on their own kid, which is totally understandable because that's how we were in the first 3, 4 weeks we didn't really entertain speaking to other people" (F5)

This father also highlighted the need for formal support from professionals, as he reflected that;

"if I didn't have the support here it would have been, it could have been really bad outcome, personally. Even like yourself [psychological services], checking on us once a week or whatever, I think that should be a must." (F5)

#### Discussion

This research has explored the lived experiences of fathers whose infants are cared for in a Scottish NICU.

As stated, interpretation of interviews elicited six overarching themes: 1) adjusting to the demands of the situation, 2) relationships with staff, 3) technology: a divided opinion, 4) becoming a father, 5) emotional reactions and 6) adaptive responses.

These themes will now be discussed in relation to relevant literature and the revised conceptual NPSM (constructs will be highlighted to the reader in bold), and their implications for fathers' support needs will be considered.

## Adjusting to the demands of the situation

Consistent with the earlier Synthesis [23] and wider quantitative [28] and qualitative [14,19,26,30,31] literature exploring fathers' experiences, fathers in this study had to juggle multiple demands. Fathers were physically exhausted from maintaining the repetitive daily routine of hospital visits. **Emotional support** from staff (i.e. listening, caring behaviours, and concern to help parents cope; such as encouraging fathers to rest and look after themselves), and **instrumental support** (i.e. assistance of any kind including financial, time, labour, environmental modifications, and good quality caregiving to the child) in the form of private rooms where fathers could rest close to their families, could help fathers manage the strenuous routine of hospital visiting.

Juggling work and the NICU could result in missed experiences and restrict the time fathers are able to spend in the NICU. This could reduce their opportunity for mastery experiences with their infant, and in turn affect their transition to parenthood through preventing the development of self-efficacy [32]. Self-efficacy is a person's belief in their ability to succeed in a particular task or in a particular situation, a person with a strong sense

of self-efficacy is thought to be more interested in and committed to activities in which they participate [33]. Bandura [33] proposes that the most effective means of developing self-efficacy is through mastery experiences; with success helping to build a strong belief in one's efficacy. Therefore, it is important to consider how to support fathers in managing these dual demands, so that they can participate and build mastery in parenting their infant. Consistent with findings from the qualitative Synthesis [23], paternity leave was identified to be an important support. Several fathers in this study, however, found accessing leave difficult and distressing.

Informational support (i.e. supportive communication and provision of information about the child and parental rights) in the form of advice on how to access paternity leave (e.g. links to social work and citizens advice) could help ease this process for fathers and support their presence in the NICU. A descriptive study reporting on fathers experience of providing their preterm infants with a programme of prolonged skin to skin care [26], suggested that instrumental support, in the form of overnight accommodation within the hospital and 24 hour access to the NICU, could support fathers through reduced travel and greater flexibility around visiting.

Quantitative research into sources of support for mothers indicates that fathers are mothers' main source of support while in the NICU [34,35]. This is consistent with the finding that fathers in this study wanted to be there for their partner and were distressed when separated. Helping fathers to remain close-by and provide support to their partners could not only avoid unnecessary distress, but could also have an important positive knock-on effect on the mother-infant relationship; as fathers' support has been found to impact on the quality of mothers' involvement with their infant [36]. This adds further weight to the need for **instrumental support** that facilitates fathers' presence in the NICU.

Consistent with findings from the Synthesis [23] fathers in this study put aside their own feelings and focused on their partner. They saw that the professionals were looking after their baby, and prioritised looking after mum. For several fathers, this involved shielding their partner from the wider family, particularly grandparents. They had the difficult job of being the 'bad guy', who placed sanctions around visiting. The Family Lifecycle Model [37] recognises that an important task for new parents is realigning their relationships with their family of origin to include grandparental roles. NICU staff could provide **parental esteem support** (i.e. actions that respect, enhance, support the parental role, and (as suggested by the earlier Synthesis) social support) to help fathers manage this tricky task. For example, discovering parents' preferences around family visiting and designing individual visiting schedules.

## **Relationships with Staff**

Fathers' stories depicted a changing power dynamic between themselves and staff; over time fathers grew gradually more assertive, and took a greater role in their infant's care. An initial power imbalance existed, however, wherein fathers felt uncertain of their role, and deferred to staff whom they viewed as having 'ownership' over their infant.

This is consistent with the finding that fathers feel 'on the sideline' in the NICU [23], and with other qualitative research exploring fathers experience in the NICU that describes fathers as waiting for permission to be involved [19,21]. Similar experiences have been reported among mothers, who have described feeling as though their baby 'belonged' to the staff [11]. This may relate to the 'Adoption Process', whereby staff unconsciously adopt an ill child [38]. Palmer, Harper and Rivinus [38] present a historical perspective on this process, in which they investigate its' manifestations within clinical teams and the child and parent. These authors assert that the 'Adoption Process' can develop in any setting in which a child is separated from his or her parents as the clinicians foster staff-patient relationships as part of diagnosis and treatment (which normally include feelings which resemble those between parent and child). The 'Adoption

Process' takes place when such feelings dominate and are enacted, unrecognised by patients and staff, to the exclusion of the parents. When this happens, Palmer et. al. [38] suggest that diagnosis and treatment are disrupted.

Health care providers, therefore, must be aware of this 'adoption' process, and provide **parental esteem support** to respect and enhance fathers' role (i.e. include fathers in decision-making and infant caregiving). The need for **instrumental support** in the form of overnight accommodation is again reinforced, as restrictions on overnight stays has been found to undermine fathers' feelings of ownership over their child [26].

Fathers' stories conveyed the fragility of their trust in the staff caring for their infant. They were uncertain and untrusting of the monitoring systems in place, and suspected that they were not being fully informed. This has not been reported elsewhere in the literature, but highlights the necessity for **informational support** to alleviate fathers' concern.

The provision of a tour of the NICU on arrival, information on the safeguards in place, and an explanation of what the many beeps and figures on the monitors mean, could support fathers' confidence in their infants care. Since completing data collection, the NICU housing this research has begun inviting parents to join ward rounds to allow parents to be part of the decision making process. Such practices facilitate transparency, and could alleviate fathers' suspicion that they are being kept in the dark.

Consistent with the fathers need for 'socio-emotional' support identified within the earlier Synthesis [23], relationships with staff were found to be important for fathers in this Scottish NICU. The therapeutic alliance between patient and therapist is recognised as a critical factor in successful psychotherapy [39]. Therefore, the tendency of fathers in this study to form alliances with certain staff could be highly adaptive, and should be nurtured. Findings from the current study suggest how such

alliances could be developed; the fathers favoured staff whom they had gotten to know, perhaps because they were then able to trust that they were the experts on their child, and felt more able to open up to them.

Consistent with qualitative interpretive research exploring fathers' experiences of preterm infants in the NICU [20], fathers in this current study also favoured staff whom they believed genuinely cared for them and their baby. Fathers indicated that staff could demonstrate that they cared through 'little things' like writing personal notes in the babies' diaries, and through humour. This validates the importance of **instrumental support** in the form of good quality care provided to the child, and **emotional support** for the development of a positive 'father-healthcare provider alliance', to fathers.

The preference for information to be shared simply, consistently and sensitively (i.e. allowing hope where possible), among fathers in this study was consistent with the findings from the earlier synthesis that information could be a 'double edged sword' [23]. Fathers in this study also indicated their preference for receiving information directly from consultants, as this was considered more reliable, and increased their sense of control over their infant's care.

The importance of simply communicated information is recognised by the finding that jargon can increase fathers' anxiety and reduce their involvement in their infant's care [21]. The benefits of allowing hope where possible is indicated by health research, for example findings from a descriptive correlational study that explored hope and coping in patients with various cancer diagnoses demonstrated that hope can support coping [40].

## Technology; divided opinion

The technological environment evoked strong emotional reactions for all fathers. Consistent with the findings that fathers' anxiety is partly related to the technological environment [23] and that fathers experience machines

as barriers to their baby [19], fathers in this study reported that the monitors could be distracting and anxiety-provoking. At other times, however, and for other fathers, the machines were a source of reassurance.

Therefore, opinions are divided, both across and within fathers, as to whether the machines are helpful or unhelpful. As such, consistent with the recommendations from another qualitative study in the neonatal setting [41], **instrumental support** should include carefully designed equipment so that it is accessible to fathers who find it helpful, but discreet enough for fathers to ignore if they wish (e.g. rotatable screens).

## Becoming a father

Fathers' stories suggested that becoming a father was a process facilitated by contact and participation. Consistent with findings from the Synthesis [23] and wider qualitative research exploring fathers' experiences of having a preterm infant cared for in a NICU [11,13,14,26], none of the first-time fathers immediately connected to their baby or to fatherhood. Research suggests that this is not unusual, as it can be weeks before first-time fathers' of full-term babies really feel like fathers [30]. Therefore, an important aspect of **parental esteem support** may be normalising this process for fathers.

Any barrier to the development of a secure parent-infant attachment, however, is to be avoided. Particularly as a review of the literature on the relationship between infants' attachment and future development [42], highlights that a secure attachment can support infants' social, emotional and neurological development. Fathers in the current study identified a number of barriers to connecting with their baby and their new role; these barriers have important implications for how staff in the NICU could help to support father-infant attachment.

Firstly, fathers in the current study identified that being unable to take their infant home made it hard to feel that the baby belonged to them. Taking

their infant home may therefore symbolise taking ownership, and difficulty connecting with their baby while in hospital may be related to father's sense that the baby 'belongs' to the NICU. This again highlights the need for staff to be wary of falling into the 'adoption process' [38].

Secondly, fathers' inability to hold their infant and engage in typical parenting behaviours prevented several fathers from feeling like a father. This is consistent with findings from a large scale research project which studied the parental attachment of high and low risk women and their partners at the first week postpartum and 8 months following birth [43]. This research suggested that delayed parent contact following a premature birth could be a barrier to the development of the parent-child relationship, and highlights that an important part of **parental esteem support** is facilitating fathers' contact with their baby as early as possible.

Finally, the baby's fragility was also identified to be a barrier to bonding. As appearance has been found to be an antecedent to bonding [44], a preterm infants' appearance compared to that of a full-term baby may be a barrier for fathers. Further, the infant's fragility may increase fathers' uncertainty for their infant's survival, and may cause an unwillingness to attach to a baby that could die. This indicates the importance of staff providing **emotional support** in the form of reassurance and hope where possible to support father-infant attachment.

Consistent with findings from the Synthesis [23], fathers in this study associated holding their infant for the first time, and being actively involved in their infants care, with bonding. The importance of holding to fathers' connection with their baby and new role has been well established by qualitative research in the neonatal setting (11,17,15,26,31,45]. **Parental esteem support** in the form of facilitating fathers' contact with their baby and involvement in the NICU is therefore important for fathers in the NICU. In light of initial power imbalance discussed above, the onus is on staff to initiate this. This support is particularly important in light of the body of

qualitative research highlighting fathers' apprehension around contact with their baby for fear of causing harm [16,20,21,31].

#### **Emotional reactions**

Having their preterm infants cared for in a NICU evoked a wide-range of emotions for fathers in this study. Consistent with the finding that fathers are 'anxiously pre-occupied' with mum and baby' [23], most fathers in this study expressed anxiety around their infant's immediate and future outcomes. This indicates fathers' need for **emotional support** (e.g. caring behaviours from staff, and access to psychological services) and **informational support** (e.g. accurate information on their infants condition) to alleviate this stress.

As their infant's conditions fluctuated, fathers described riding an emotional rollercoaster of ups and downs. The NICU, in which this research took place, is structured so that infants progress through three levels of care; the intensive care unit (ICU), the high dependency unit (HDU) and the special care baby unit (SCBU). Fathers linked their highs and lows to their infant's transitions between these rooms. Moving back a room was a real blow. This finding suggests that in environments such as this, where setbacks are so visible, it is important that staff be sensitive to the impact on fathers, and that **emotional support** in the form of professional psychological services are available to support fathers through the lows.

Another emotion identified among fathers in this study, which was not identified in the earlier Synthesis [23], was frustration. A common source of frustration for fathers was feeling stuck in the NICU, particularly as fathers reached the SCBU and felt that they were nearly home. At this stage fathers appeared to relinquish their patient 'one-day-at-a-time' strategy, and allowed themselves to hope and look ahead, which released strong feelings of impatience. In reality babies' progress often slows at this stage and they are likely to remain in the SCBU for some time. **Informational support** (e.g. sensitively communicated information on

common timeframes at this stage) could help to manage fathers' expectations and prepare them for this 'lull'. Further, **instrumental support** in the form of private spaces (where fathers could escape to and unwind), may help to lessen fathers' sense of being trapped.

In the first few days, a number of fathers described experiencing shock. Consistent with qualitative literature in this area, fathers in this study described feeling disoriented, disconnected and numb, and were unable to absorb information [12,14,15]. Staff must be mindful of this experience, and ensure that any information is repeated and backed-up in writing if appropriate.

Further, while these reactions, and the anxiety and frustration described above, are to be expected, if they persist and go on to affect fathers' daily functioning, they may be indicative of Acute Stress Disorder (ASD) or Post Traumatic Stress Disorder (PTSD). The American Psychiatric Association [46] defines PTSD as being brought about by fearful and threatening experience in which the individual experiences a lack of control and fears for their own or another's safety [46]. An unexpected preterm birth, where both mother and baby may be at risk, would certainly fit these criteria. A quantitative study of 130 parents of infants in NICU, found that within the first three to five days of admission 32% of parents reported subclinical ASD, and at 30 days 8% of fathers qualified for a diagnosis of PTSD [47]. This highlights the real risk to both mothers and fathers, and the need for **emotional support** in the form of psychological services to be present in the NICU in order to help identify and manage symptoms.

## **Adaptive responses**

A number of adaptive responses were identified among fathers in this Scottish study that were not identified in the Synthesis of research in this area [23]. All adopted self-protective strategies. For example, all strove to remain hopeful (an effective coping tool [40]) through tracking signs of their infant's progress. **Informational support** from staff could help fathers utilise this adaptive strategy through informing them of any

improvements, for example through recording infant's daily progress in shared diaries.

Fathers also 'relinquished control'; they placed confidence in staff and entrusted them with their infants care. This self-protective strategy was particularly true of fathers whose work made it difficult for them to sustain a continued presence at the NICU; a finding that is supported by the finding that fathers who struggle to get paternity leave delegate their infants' care to staff [11]. The only father in the current study who did not describe feeling anxious, spoke of his great confidence in the hospital and staff. This father, in addition to already being a parent, was self-employed and did not have access to paternity leave. The research team considered his confidence adaptive, as he was less able to be present in the NICU to watch over his baby.

Fathers who 'relinquished control' in this study also described 'emotionally shutting off', and not allowing themselves to become too attached to their baby in case it died. This is in line with a longitudinal descriptive study [45] that explored fathers' perceptions of, and feelings for, their infants, and found that fathers' attachment is facilitated by confidence in their infant's survival. Although this was an understandable and protective strategy, it was not one that fathers in this study were comfortable in admitting. Therefore, nurses could support fathers' attachment by providing **emotional support** in the form of reassurance and hope where possible.

Consistent with research in this area investigating both fathers and mothers [11], fathers in this study described 'taking it one day at a time'; a strategy of not looking too far ahead for fear disappointment. As discussed above, difficult feelings of frustration emerged when fathers began to relinquish this strategy. This suggests that, in addition to protecting fathers from possible disappointment, the 'one day at a time' strategy could help them remain patient through this long journey. Therefore encouraging this strategy could be a helpful form of **emotional support**.

Fathers also engaged in 'problem-focused coping'; actively taking steps to alleviate their distress. Two problem focused coping approaches were identified:-

Firstly, fathers independently sought information that did not require them to rely on asking staff. They carefully watched their surroundings, namely staff and the machines, seeking information and guidance. This is an adaptive strategy, as previous qualitative research in this setting suggests that actively seeking information helps to foster a feeling of control and security among fathers [14,17]. This highlights the need for **informational support** to include independent information sources in the NICU environment, for example, charts that fathers can read. Further, as fathers can develop self-efficacy through observing staff, which may in turn facilitate their transition to parenthood [32,33], modelling could be a useful form of **informational support**.

Secondly, fathers engaged in active coping; by seeking opportunities to be involved in caring for their baby they created a place for themselves in the NICU. This was an adaptive strategy as existing qualitative research exploring fathers' experience in the NICU suggests that engagement in everyday tasks of parenting allows fathers to feel more in control [14,26] and self-efficacious [32]. This again highlights the importance of **parental esteem support** in the form of facilitating fathers' involvement in their infants' care.

Fathers also employed two distinct social strategies. Firstly, every father in this study described taking comfort from passive social comparisons. Social Comparison Theory was first proposed by Festinger [48]; Wills [49] then developed this and introduced the concept of Downward Social Comparisons (DSC). He emphasised the positive effects on one's subjective wellbeing from comparing one's own personal situation to a person or group that is perceived as worse off. DSC is common among populations under health threat [50], and is prevalent among mothers of medically fragile infants; specifically, correlates of selective comparisons

by mothers of high-risk infants showed that mothers were especially likely to make downward comparisons [51].

When fathers compared themselves to families of full-term infants, however, they felt worse. Upward Social Comparisons (USC) can provide inspiration, motivation and hope [52], however, a more helpful USC for fathers of preterm infants may be to parents of other preterm infants who are doing well, or have already been successfully discharged. The open plan design of the NICU provided **instrumental support** by enabling social comparisons among fathers in this study.

Secondly, fathers valued 'matched social support'; talking to others with similar experiences helped fathers feel understood. This desire for matched social support is consistent with qualitative research in this area [12,14,19]. This strategy is also consistent with Fear-Affiliation Theory [53]; which proposes that anxiety will increase a person's need to affiliate with others who are going through the same situation, or who could help them through the stressful event. Affiliation with others who have been in a similar position could reduce one's anxiety through generating feelings of similarity and creating access to information [54].

The open plan design of the NICU creates natural opportunities for families to gain matched social support from each other, however, **parental esteem support** in the form of facilitated social support from other parents (formal parent support groups, as suggested by one father in this study) should also be provided.

Interestingly, however, this study identified that matched social support may not be valued by fathers for the first 4-5 weeks, as they initially prefer to maintain an introverted focus on their own baby. Consistent with qualitative research in this area, this study also identified a desire for formal emotional support from professionals [12,14,15] highlighting again the importance of having **emotional support** in the form of specialist psychological services available to fathers.

#### Conclusion

This study offers an in-depth understanding of fathers' experiences of having their preterm infant cared for in a Scottish NICU, and has helped to develop a clearer understanding of fathers' support needs.

Findings from this study validate the relevance of the constructs of support outlined within the Nurse Parent Support Model for fathers in the NICU, and corroborate the need for adaptations to this model as suggested by a recent Synthesis [23]. Specifically, that (consistent with House's [25] original definitions of support) environmental adaptations and financial support be included (along with good quality caregiving) under the construct of 'instrumental support', and social support be incorporated into the construct of 'parental esteem support'. Finally, findings from this study indicate how this model could be implemented in clinical practice to inform the provision of Family Centred Care and thus promote parent and infant wellbeing.

# **Strengths and limitations**

A strength of this study was the methodological rigour with which it was carried out. Further, all fathers in this study reported that they enjoyed the interview, as one father said "It's good to get it out actually" (F6). This is in line with the finding that 'exit interviews' can be helpful for fathers [17].

One limitation of this study is its specific focus on fathers of premature infants who survived. This focus was necessary to ensure homogeneity, however it means that the findings cannot be claimed to represent fathers of infants who were admitted for other reasons, or of the unique experience of fathers of infants who died. Similarly, the fact that all fathers who consented to take part this study were white and English speaking means that the current findings cannot be claimed to represent non-English speaking non-white fathers.

Secondly, the time point at which interviews took place could been seen as a limitation. Interviewing around the point of discharge may have lead to positively biased stories, as at this point fathers had successfully completed their journey. However the research team were considered that taking fathers away from their family to conduct the interview at an earlier time point would be insensitive.

Thirdly, this study explored fathers' experiences as described at just a single time point, which meant that fathers did not have the chance to share any later recollections or opinions at a second appointment, or to get to know the interviewer and increase their comfort around her through repeated meetings. This limitation was addressed by: 1) beginning each interview with an informal chat, and 2) inviting participants to raise any additional topics before finishing.

Finally, the interviewer's gender may have been a limitation as it has been suggested that an interviewer may be more attuned to their own gender [55].

## **Future directions**

As highlighted above, this study specifically focused on fathers of preterm infants who survived, and included only English speaking, white fathers. In order to understand the unique needs of the diverse population of fathers in the NICU, in particular those of infants who have died, further qualitative research into their experiences is needed.

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## Chapter 3: Advanced Clinical Practice I - Reflective Critical Account

## **Expanding my Psychological Toolkit**

## **Abstract**

In this reflective account I use a model of supervision to take a developmental overview of my clinical practice. I specifically focus on the development of my formulation skills, but also touch on intervention and multidisciplinary team working. Frameworks for reflexive practice guide my consideration of experiences I have identified as being key in the development of my clinical practice. Through these experiences I can observe how I have grown from an eager, but highly anxious and 'tunnel vision-ed' first year trainee, to a clinician with a wider, and more patient-focused approach.

## **Chapter 4: Advanced Clinical Practice II - Reflective Critical Account**

## From Research Assistant to Chief Investigator

## **Abstract**

A developmental model of supervision provided an overarching structure within which I have reflected on the development of my research skills over three years of Doctoral training.

Learning experiences which I feel have been critical in my professional development are reflected on here using two separate frameworks for reflexive practice.

Within this reflective account I have explored and observed my development from a motivated, but overly dependent and self-doubting trainee researcher, towards becoming a more autonomous and competent scientist practitioner.

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## Appendix 1: Guidelines for submission to the Journal of Psychosomatic

## Research



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## DESCRIPTION

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#### INTRODUCTION

#### Types of article

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For inquiries relating to the submission of articles (including electronic submission) please visit this journal's homepage. For detailed instructions on the preparation of electronic artwork, please visit <a href="http://www.elsevier.com/artworkinstructions">http://www.elsevier.com/artworkinstructions</a>. Contact details for questions arising after acceptance of an article, especially those relating to proofs, will be provided by the publisher. You can track accepted articles at <a href="http://www.elsevier.com/trackarticle">http://www.elsevier.com/trackarticle</a>. You can also check our Author FAQs at <a href="http://www.elsevier.com/authorFAQ">http://www.elsevier.com/authorFAQ</a> and/or contact Customer Support via <a href="http://support.elsevier.com">http://support.elsevier.com</a>.

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## Appendix 2: Search terms

## CINAHL:

1. neonatal intensive care unit, OR neonatal intensive care, OR NICU, OR neonatal nursing, OR neonatal intensive care nursing, OR preterm infant (free term), OR premature infant, OR low birth weight infant, OR very low birth weight infant,

## AND

2. fathers, OR father-infant relations, OR fatherhood, OR paternal behaviour OR paternal role OR paternal attitudes OR father (free search), OR paternal

## AND

3. qualitative studies, OR field studies, OR qualitative research, OR Phenomenology OR interpretive phenomenology, OR content analysis, OR thematic analysis OR thematic content analysis OR narratives OR experiences (free search)

## MEDLINE and EMBASE:

1. neonatal intensive care unit, OR neonatal intensive care, OR NICU (free term), OR neonatal nursing, OR preterm infant (free term), OR premature infant, OR extremely premature infant OR low birth weight infant, OR very low birth weight infant, OR extremely low birth weight infant,

## AND

2. fathers, OR father-child relations, OR paternal behaviour OR paternal deprivation, OR father\* (free search), OR paternal (free search)

## AND

3. qualitative research, OR qualitative (free search), OR interpretive phenomenology, OR thematic content analysis OR experience\* (free search) narratives OR interview OR personal narratives

Psychology & Behavioural Sciences Collection and PsychINFO:

1. neonatal intensive care unit, OR neonatal intensive care, OR NICU, OR preterm infant, OR premature infant, OR extremely premature infant, OR low birth weight infant, OR very low birth weight infant, OR extremely low birth weight infant

AND

- 2. fathers, OR father-infant relations, OR fatherhood, OR paternal, AND
- 3. qualitative research, OR interpretive phenomenology, OR thematic content analysis OR personal narratives OR experience\*

Appendix 3: Quality Assessment Framework [18] (12 essential criteria plus prompts)

## 1. Clear Statement of and rationale for research question/aims/ purposes

- Clarity of focus demonstrated
- Explicit purpose given such as descriptive, explanatory, intent, theory building, hypothesis testing

## 2. Study thoroughly contextualised by existing literature

- Link between research and existing knowledge demonstrated
- Evidence of systematic approach to literature review, location of literature to contextualise the findings or both

## 3. Method/ design apparent and consistent with research intent

- Rationale given for use of qualitative design
- Discussion of epistemological/ ontological grounding

## 4. Data collection strategy apparent and appropriate

- Rational explored for scientific qualitative method e.g. ethnography, grounded theory, phenomenology
- Discussion of why particular method chosen is most appropriate/ sensitive/ relevant for research given research questions or aims
- Setting appropriate
- Were data collection methods appropriate for type of data required and for specific qualitative method?
- Were they likely to capture the complexity/ diversity of experience and illuminate context in sufficient detail?
- Was triangulation of data sources used if appropriate?

## 5. Sample and sampling method appropriate

- Selection criteria detailed and description of how sampling was undertaken
- Justification of sampling strategy given
- Thickness of description likely to be achieved from sampling
- Any disparity between planned and actual sample explained

## 6. Analytic approach appropriate

- Approach made explicit e.g. thematic distillation, constant comparative method, grounded theory
- Was it appropriate for the qualitative method chosen?
- Was data managed by software package or by hand and why?
- Discussion of how coding system/ conceptual frameworks evolved
- How was 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 theoretical stance
- Did research participants have any involvement in analysis?
- Evidence provided that data reached saturation or discussion/rationale if it did not
- Evidence that deviant data was sought or discussion/ rationale if it was not

## 7. Context described and taken account of in interpretation

- 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

## 8. Clear audit trail given

 Sufficient discussion of research process such that others can follow decision trail

## 9. Data used to support interpretation

- Extensive use of field notes entries/ verbatim interview quotes in discussion of findings
- Clear exposition of how interpretation led to conclusions

## 10. Researcher reflexivity demonstrated

- 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

## 11. Demonstration of sensitivity to ethical concerns

- Ethical committee approval granted
- Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants
- Evidence of dilemmas met and how resolved in relation to ethical issues
- Documentation of how autonomy, consent, confidentiality and anonymity were managed

## 12. Relevance and transferability evident?

- 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 with 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 and increases understanding
- Significance for current policy and practice outlined
- Assessment of value/ empowerment for participants
- Outlines further directions for investigation
- Comment on whether aims/ purposes of research were achieved

## Appendix 4: Fatally Flawed Guideline [26]

Appraisal prompts for informing judgements about whether papers are 'fatally flawed'	Yes or No?
Are the aims and objectives of the research clearly stated?	
Is the research design clearly specified and appropriate for the aims and objectives of the research?	
Do the researchers provide a clear account of the process by which their findings we reproduced?	
Do the researchers display enough data to support their interpretations and conclusions?	
Is the method of analysis appropriate and adequately explicated?	

The above criteria above was adapted from those by the National Health Service (NHS) National Electronic Library for Health for the evaluation of qualitative research by Dixon-Woods et al., [26], in order to identify 'fatally flawed papers'.



# A Qualitative Study of Fathers' Experiences of a Scottish Neonatal Intensive Care Unit

## Who can I contact?

If you have any queries about any aspect of the study or require further information, please do not hesitate to contact our independent advisor Jill Ogston via the address below:

Dr Jill Ogston
East Ayrshire Child and Adolescent Mental Health Service
North West Area Centre
Western Road
Kilmarnock
KA3 1NQ

Tel: (01563) 578540

## Introduction

You are being invited to take part in a project looking at Scottish fathers' experiences of having their preterm infants hospitalised in a neonatal intensive care unit (NICU), with a view to developing a clearer understanding of their support needs. Before you decide if you would like to participate it is important that you know a bit more about the project and what this will involve. Please take time to read the following information carefully and raise any questions you may have with the project worker (contact details are provided at the end of this sheet).

## What is the study about?

Recent international research into fathers' personal experiences in the NICU has offered increased insight into their needs. However, as yet, no investigation has been conducted into the experience of fathers in Scotland. Therefore, there is a need for a better understanding of fathers' experiences of having their preterm infant cared for in a Scottish NICU. It is hoped that this understanding will facilitate the provision of effective family centred care.

## Why have I been chosen?

As a father of an infant cared for in a Scottish NICU, your experience can help us develop a clearer understanding of what other fathers in this situation need to support them.

## Do I have to take part in the study?

No. Participation in this study is entirely voluntary. This information sheet is for you to keep and will help you decide if you would like to take part. If you choose

not to participate in this project, it will not affect the care you or your family receives.

## What will participation involve?

If you choose to participate, you will be invited to meet with a member of the research team (Trainee Clinical Psychologist) to discuss your experience of having your infant cared for in a NICU. This will last approximately 60 minutes, and will be offered at a time of your choosing to minimise inconvenience to yourself. This interview will be recorded and anonymous quotes may be used with your consent.

## Will my participation in the study be kept confidential?

The information you provide will be kept <u>strictly confidential</u>. You will not be personally identified in any of the study results or reports. Your responses will be given anonymously, and the data will be kept securely.

## What will happen to the results of the study?

The results will be written up into a thesis and form part of a Doctoral programme in Clinical Psychology, and may be published. You will not be identified in this, or in any other report resulting from the study. You can request a summary of the findings if you would like. You will not be identified in this summary.

## What are the possible disadvantages and risks of taking part?

There are not thought to be any risks or disadvantages in taking part. However, if you feel distressed at any time during the interview you will have the option to stop. If you feel upset after the interview, please contact the researcher who will be able to direct you towards the appropriate support. If you have any concerns or complaints regarding the way you have been approached or treated during this research, please contact us at any time using the contact details above. You can also make a complaint to NHS Ayrshire and Arran's Patient Advice & Liaison Service at:

Patient Relations & Complaints Eglinton House Ailsa Hospital Dalmellington Road AYR KA6 6AB

## What are the possible benefits of taking part?

We cannot promise that this study will help you directly, but it is hoped that through a better understanding of fathers' experiences of having their preterm infants cared for in a Scottish NICU, health care providers will be facilitated in meeting fathers support needs.

## Who is organising the research?

This study is being organised by Kim Robertson, a Doctorate student from the University of Glasgow. This is in collaboration with Dr Suzy O'Conner, also from the University of Glasgow, and Dr Marisa Forte from NHS Ayrshire & Arran.

## Who has reviewed this study?

The study has been reviewed by the ethics committee, clinical psychology research and clinical governance committee, and Ayrshire & Arran's Research & Development team.

## What should I do now?

**If you wish to take part:** Please complete the consent form and return it in the Freepost envelope. You will then be contacted by a member of the research team and invited to an interview.

Thank you for taking the time to read this Information Sheet.



## **Consent Form**

Title of Project: A Qualitative Study of Fathers' Experiences of a Scottish

Neonatal Intensive Care Unit and Nurses' Experiences of Providing

Paternal Support

Name of Researcher: Kim Robertson

<u>boxes</u>		<u>Ple</u>	ease Initial all
have had the op	I have read and t (V1 16.9.13) for the portunity to conside and have had	ne above study. I r the information,	
I understand that     I am free to with     reason.	my participation is volution at any time w		
3. I agree to take pa	ırt in the above study	/.	
I confirm that I recorded.	am happy for my	interview to be	
		Contact phone nu	mber(s)
Name of Participant	Date	Signature	
Name of Researcher	Date	 Signature	

## Initial opening questions

General conversation (e.g. Hello how are you? How has your day been) If you felt comfortable discussing it, I would be interested in hearing your story of how you came to be here, perhaps, starting from the birth?

## General prompts

Can you tell me more about that?

Can you help me understand what about that helped you?

What of those do you believe is most important?

What happened next?

Specific questions asked following fathers narrative (if not covered in narrative); drawn from themes emerging in previous literature

I wonder whether you were given any information, or would have liked to be given any information, to help you?

I wonder if you were given, or would have like to have been given, any emotional support to help you cope?

I wonder if there were any particular actions on the part of professionals working with you that you felt helped you, (or would have helped you), to develop your role as a father?

I wonder if there were any aspects of care for your child that you had, or would you liked to have had, to support your own coping?

## Ending questions

Is there any advice you would give to other parents in this situation to help them cope?

What advice would you give to professionals working with you and your family to help them support parents of premature infants in the NICU? Is there anything else you think I should know to better understand how to support fathers of premature infants in an NICU?

Is there anything you would like to ask me?

How has this experience of speaking with me today been for you?

# Appendix 8: Six-Step Heuristic Framework [25]

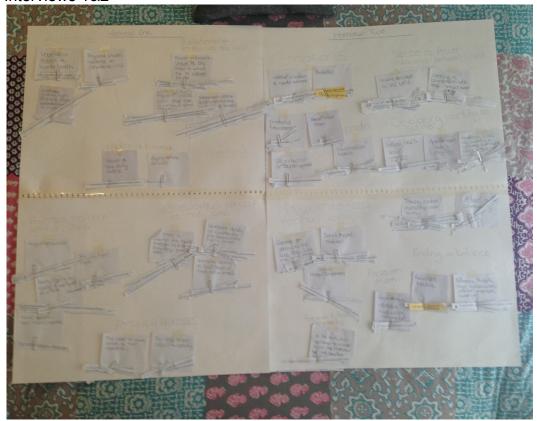
Step 1	Reading and re-reading to focus on, and immerse oneself within
	the individual's narrative.
Step 2	Initial noting to engage with the text in detail (e.g. via
	commenting on the interviews descriptively, linguistically, and
	conceptually), and investigate possible meanings that emerge to
	move analysis towards conceptual interpretation.
Step 3	Developing emergent themes and clustering them together by
	mapping the interrelationships, connections and patterns across
	notes taken during the initial noting
Step 4	Searching for connections and emergent themes in order to
	chart how the emerging themes fit together and highlight key
	aspects of participants' accounts. This four-stage process was
	repeated for each case.
Step 5	Moving to the next case being careful to treat each interview on
	its own terms through, as far as possible, bracketing the ideas
	emerging from the previous case(s) while working on the next.
Step 6	Looking for patterns across cases and producing a graphic
	representation of the themes and sub-themes. This process
	facilitates the generation of detailed descriptions of patterns of
	meanings, and reflections on shared experiences.

## Appendix 9: Sample extract of analysis process

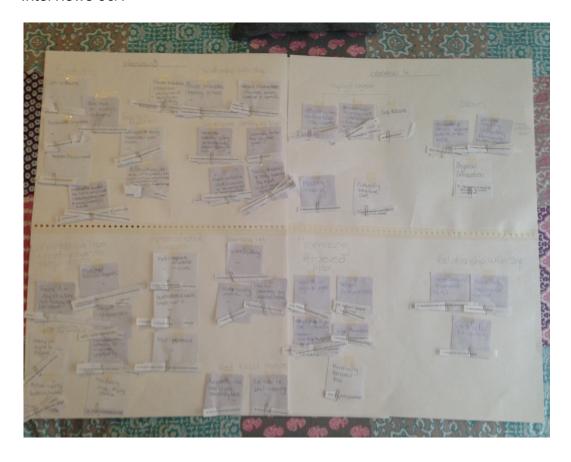
D: So it was pretty scary and that, and I mean, 4 hours later he came along, it wasn't straightforward, he was a small baby, but she really struggled she really really did, she did it with no had no pain relief or anything, she said the gas was making her sick, so she just yes.... It was scary to see coz obviously my 3. Focus on mum's health and wellbeing first baby and very scary to see...and when he was Comment: Focused on mum's wellbeing 4. Anxious and uncertain born I don't know if you know but they leave them (D). I wonder if he felt a sense of being for about 60 seconds just to let the placenta do its helpless? (C) wee bits and stuff and when I seen him lying there you think Jinx this poor wee thing and then he gave a wee grumble out and you think oh Jinx and 5. Uncertain, of own authority/rights/self doubt thought to myself should I just take a picture and I Comment: Father expressed the fear of this thought no but I really wish I had took a picture to premature birth (D) language here is stilted show my wife about it and then when they picked and jumpy, frequent use of 'jings' which I him up....that lady we spoke to, X? X, she was the think reflected the high emotions of this one that picked him up and done all the wee bits and experience (L) bobs with him and I was watching over her and I was talking to my wife and she was saying what's Comment: The father had wanted to take a 6. Value containment and reassurance at this happening and X turned round and said flook photo of his son, but 'though no'; I wonder if highly stressful and uncertain time everything we are doing is totally normal you have he was feeling watched/judged? That he would have need permission from the staff? got the rest of your life to worry about this little From this action I wonder whether he did not fella'...and I thought Jinx that's quite nice you know, feel in charge of his own son? (C) but see when you see it someone taking them away 10/1/14 16: and doing the bits and bobs its absolutely terrifying it Comment: Father's account reflected his is and you think Jinx is everything okay because you gratitude/appreciated for explanations and reassurance around of what is being done want to hear a cry but you don't hear anything like with his baby (D). I wonder if this desire to be that because he is too wee, you just hear wee appraised of actions relating to his son, mumbles, a wee mumble and that was all you kind of reflects, in addition to his need for anxieties heard and I got a wee look and then they had to take to be contained, the fathers need for the him away to ICU to intensive care, but it's kind of sad parents rights to be included met? Comment: Here I wonder if there was some resentment in the little contact he got to have K: And did you have any preparation for knowing with his son before x was taken away? (C) you'd be coming here? im robertson 10/1/14 16:30 Comment: sense of dad watching, confused D: We got a little visit, we got a little......because we and scared (D), with no say or involvement in kept hoping that X would hold on, even though her what is going on (C). I wonder whether this

Appendix 10: Individual interview super and subordinate themes

Interviews 1&2



Interviews 3&4



## Interviews 5&6



# Appendix 11: Table of themes

Super-ordinate themes	Sub-ordinate themes	Breakdown
Adjusting to the	The daily grind (F: 1-6)	
demands of the situation	Being there for mum	Painful separations (F: 2, 3, 6)
		Looking after mum (F: 2-6)
	Juggling work and the NICU (F: 2-6)	
Relationships with	The balance of power (F: 1-6)	
Staff	Fragile trust (F: 3, 5, 6)	•
	Identifying Allies (F:1-6)	•
	Communication (F: 1-3, F5)	•
Technology: a divided opinion (F: 1-6)		
Becoming a father	Initial disconnection (F: 1-3, 5, 6)	
	Connecting through contact (F: 1-3, 5, 6)	
Emotional reactions	Anxiety for baby (F: 1- 3, 5, 6)	
	Ups and downs (F: 1-3)	•
	Frustration (F: 1, 2, 3, 5, 6)	
	Initial shock (F: 2, 4, 5, 6)	
Adaptive responses	Self protection	Remaining hopeful tracking progress (F: 1-6)
		Relinquishing control (F: 4-6)
		Emotionally shutting off (F: 4-6)
		Pacing: not looking too far ahead (F: 1, 3, 6)
	Problem Focused coping	Independent information seeking (F: 1-3, 5, 6)
		Active coping: feeling useful (F: 1, 3, 5, 6)
	Social strategies	Social comparisons (F: 1-6)  Matched social support (F: 1-6)

<sup>\*</sup>Information in parenthesis (e.g. F1) indicates where fathers' quotes exist to show the density of evidence for each theme.

Appendix 12: Contextual information on NICU

Staff 60 staff including; consultants, midwives, nurses, 6 Advanced Neonatal Nurse Practitioners, and input from a Clinical Psychologist (2 sessions per week).  Physical layout 20 cots in this unit; 5 in ITU, 4 in HDU, 11 in SCBU. There are also 2 family rooms and 3 quiet rooms  Support from Voluntary organisation  Strong links with SANDS (Stillbirth and Neo-natal Death Society) and BLISS Scotland. There is neonatal staff representation at SANDS meetings to feedback any pertinent issues to help improve care. This feedback system also helps the unit to recognise and build on what they are doing well. A BLISS champion is in the unit every second Wednesday to support parents and a Facebook page has been set up as support forum.
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Wednesday to support parents and a Facebook page has been set up as support forum.
page has been set up as support forum.
Davage control The unit have set up a number of initiatives to
Person centred The unit have set up a number of initiatives to
approach support patents in the unit; Memory boxes for
babies who have died, the opportunity for
photographs, private rooms for spending time with
babies when possible, and a graduation board of
babies leaving the Neonatal unit.
Actions to promote The unit promotes skin-to-skin and kangaroo care
parent involvement and have set 'care times' so parents don't miss out
on baby's cares (bathing, nappy changing etc). The
availability of private family rooms is also aimed to
support parents' involvement.
Recent and upcoming   • Parents with a baby in ITU who wish to join the
development since Consultant on the ward round are now able to
data collection do so. Parents therefore are encouraged to feel
part of the decision making process.
<ul> <li>Parents have the opportunity to meet with</li> </ul>
consultants regularly via consultant time
slots/booked via a diary held by staff
(availability 11am- 5pm) for a weekly meeting
with consultant (once weekly as a minimum)
and as often as parents feel is needed.
A mentoring system (via BLISS) where
someone who has previously had a baby in the
unit can act as a mentor to another parent is
just about to start.
<ul> <li>The same team of professionals now meets</li> </ul>
babies and families in unit and follows them up
as part of the Neurodevelopmental service,
which increases parental confidence in follow-
up support.

## Appendix 13: West of Scotland Research Ethics Committee approval

# WoSRES

#### West of Scotland Research Ethics Service



Mrs Kim Robertson Psychology Department Administration Building 1055 Great Western Road Glasgow G12 OXH West of Scotland REC 5 Ground Floor - Tennent Building

Western Infirmary 38 Church Street Glasgow G11 6NT

Date 29 October 2013

Direct line 0141 211 2102

E-mail WoSREC5@ggc.scot.nhs.uk

Dear Mrs Robertson

Study title: A Qualitative Study of Fathers' Experiences of a Scottish

Neonatal Intensive Care.

REC reference: 13/WS/0262 IRAS project ID: 136123

The Research Ethics Committee reviewed the above application at the meeting held on 16 October 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Sharon Macgregor, WoSREC5@ggc.scot.nhs.uk.

#### Ethical opinion

- The Committee asked the Researcher to explain why the Participant Information Sheet and Consent Form had a different title from the Application Form. The Researcher advised that this was an error and would issue new documents with the correct title.
- 2) The Committee commented that 'No' had been ticked at A49 in the Application Form 'Will you inform the participant's GP that they are taking part in the study' yet the Participant Information Sheet stated that the GP would be informed. The Researcher advised that this was an error and the GP would not be informed.
- 3) The Committee noted that the interview would take place at the 3 month review and wondered whether this was appropriate as some fathers may be distressed if they have received bad news about their baby. The Researcher advised that she would consult with the

Nurses in the Paediatric Team before approaching the fathers as they who would be able to advise whether it was an appropriate time to conduct the interview.

- 4) The Committee noted that study would exclude fathers whose infants were either terminally ill or had died. The Committee wondered whether an opportunity had been missed to perhaps collect valuable data from this particular group which would enhance the findings of the study. The Researcher commented that the study had been designed to include a specific group at this stage. The Committee suggested that perhaps if a future study is planned then all fathers should be included. The Researcher took this comment on board.
- The Committee noted that the study would exclude those who did not speak English well.
   The Researcher commented that funds were not available for translation.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- 1) The Participant Information Sheet (PIS) requires to be amended as follows:
- a) Headed paper should be used and contact details should be at the beginning
- The header and footer states 'Patient Information Sheet'. The Fathers are not patients so this should be amended to read 'Participant'
- c) The Title of the study should be corrected as discussed.
- d) At 'Do I have to take part in the study?' the first word should be 'No'.
- At 'What will participation involve' There should be a sentence added stating that the interview will be recorded and that anonymous quotes from the interviews will be used with consent.
- At 'Will my participation in the study be kept confidential?' the sentence about informing the GP should be deleted as discussed.
- g) At 'What are the possible disadvantages and risks of taking part?' a sentence should be added stating that the NHS Complaints system is also available to the participant and contact details included.
- The paragraph 'If you do not wish to take part' should be deleted.
- The words 'Thank you for taking the time to read this Information Sheet' should be added at the end.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation

with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <a href="http://www.rdforum.nhs.uk">http://www.rdforum.nhs.uk</a>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		20 September 2013

Investigator CV		
Other: Preliminary Question Schedule for Fathers	1	20 September 2013
Other: Fathers Demographic Information	1	20 September 2013
Other: Health & Safety for Researchers Form	1	20 September 2013
Other: Research Equipment, Consumables and Expenses	1	20 September 2013
Other: CV for Suzy O'Connor (Academic Supervisor)		06 March 2013
Other: CV for Dr Marisa Forte (Field Supervisor)		15 July 2013
Participant Consent Form	1	20 September 2013
Participant Information Sheet	1	20 September 2013
Protocol	1	20 September 2013
REC application		17 August 2013
Referees or other scientific critique report		14 June 2013
Summary/Synopsis	1	20 September 2013

#### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

#### 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.

#### After ethical review

#### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- · Notifying substantial amendments
- · Adding new sites and investigators
- · Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website. Further information is available at National Research Ethics Service website > After Review

#### 13/WS/0262

#### Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days - see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

SMacgregar

for Dr Gregory Ofili

Chair

Enclosures: List of names and professions of members who were present at the

meeting and those who submitted written comments "After ethical review - guidance for researchers"

Copy to: Dr Karen Bell, NHS Ayrshire and Arran, Research and Development

# WoSRES West of Scotland Research Ethics Service



West of Scotland REC 5

Ground Floor - Tennent Building Western Infirmary 38 Church Street Glasgow G11 6NT

Mrs Kim Robertson Psychology Department Administration Building 1055 Great Western Road

GLASGOW

G12 0XH

Date 06 November 2013

Direct line 0141 211 2102

E-mail WoSREC5@ggc.scot.nhs.uk

Dear Mrs Robertson

A Qualitative Study of Fathers' Experiences of a Scottish Study title:

Neonatal Intensive Care.

13/WS/0262 REC reference: 136123 IRAS project ID:

Thank you for your letter of 1 November 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 29 October 2013

#### Documents received

The documents received were as follows:

Document	Version	Date
Participant Information Sheet	2	01 November 2013
Protocol	2	01 November 2013
Response to Request for Further Information		

#### Approved documents

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

Document	Version	Date
Covering Letter		20 September 2013
Investigator CV		
Other: Preliminary Question Schedule for Fathers	1	20 September 2013
Other: Fathers Demographic Information	1	20 September 2013

Other: Health & Safety for Researchers Form	1	20 September 2013
Other: Research Equipment, Consumables and Expenses	1	20 September 2013
Other: CV for Suzy O'Connor (Adademic Supervisor)		06 March 2013
Other: CV for Dr Marisa Forte (Field Supervisor)		15 July 2013
Participant Consent Form	1	20 September 2013
Participant Information Sheet	2	01 November 2013
Protocol	2	01 November 2013
REC application		17 August 2013
Referees or other scientific critique report		14 June 2013
Response to Request for Further Information		
Summary/Synopsis	1	20 September 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.

13/WS/0262 Please quote this number on all correspondence

Yours sincerely

Mrs Sharon Macgregor Committee Co-ordinator

Macgregar

Copy to: Dr Karen Bell, NHS Ayrshire and Arran, Research and Development Office

## Appendix 14: Ayrshire and Arran Research and Development approval



Research & Development 58 Lister Street University Hospital Crosshouse Kilmarnock KA2 0BB

Ms Kim Robertson Psychology Department Administration Building 1055 Great Western Road Glasgow

G12 0XH

7 November 2013

Your Ref

Date

KF/KLB/AMK 2013AA066 Our Ref

Enquiries to Karen Bell Extension 25850

Direct line 01563 825850 Fax 01563 825806

Karen.bell@aaaht.scot.nhs.uk Email

Dear Ms Robertson

#### A Qualitative Study of Fathers' Experiences of a Scottish Neonatal Intensive Care

I confirm that NHS Ayrshire and Arran have reviewed the undernoted documents and grant R&D Management approval for the above study.

#### Approved documents:

Document	Version	Date
IRAS R&D	3.5	23 September 2013
IRAS SSI	3.5	24 September 2013
Participant Information Sheet	2.0	1 November 2013
Protocol	2.0	1 November 2013
Preliminary Question Schedule for Fathers	1.0	20 September 2013
Fathers Demographic Information	1.0	20 September 2013
Participant Consent Form	1.0	20 September 2013
Health & Safety for Researchers Form	/	/
Research, Consumables & Expenses	/	/
Response to Ethics	1	1

The terms of approval state that the investigator authorised to undertake this study within NHS Ayrshire & Arran is: -

Kim Robertson, NHS Ayrshire & Arran

With additional investigator: -

Marisa Forte, NHS Ayrshire & Arran

The sponsors for this study are NHS Ayrshire and Arran.

This approval letter is valid until 7 January 2015.

Regular reports of the study require to be submitted. Your first report should be submitted to Dr K Bell, Research & Development Manager in 12 months time and subsequently at yearly intervals until the work is completed.

Please note that as a requirement of this type of study your name, designation, work address, work telephone number, work e-mail address, work related qualifications and whole time equivalent will be held on the Scottish National Research Database so that NHS R&D staff in Scotland can access this information for purposes related to project management and report monitoring.

In addition approval is granted subject to the following conditions: -

All research activity must comply with the standards detailed in the Research
Governance Framework for Health and Community Care

www.cso.scot.nhs.uk/publications/ResGov/Framework/RGFEdTwo.pdf
and appropriate
statutory legislation. It is your responsibility to ensure that you are familiar with these,

however please do not hesitate to seek further advice if you are unsure.

You are required to comply with Good Clinical Practice (ICH-GCP guidelines may be found at <a href="https://www.ich.org/LOB/media/MEDIA482.pdf">www.ich.org/LOB/media/MEDIA482.pdf</a>, Ethics Guidelines, Health & Safety Act 1999 and Data Protection Act 1998.

If any amendments are to be made to the study protocol and or the Research Team the Researcher must seek Ethical and Management Approval for the changes before they can be implemented.

The Researcher and NHS Ayrshire and Arran must permit and assist with any monitoring, auditing or inspection of the project by the relevant authorities.

The NHS Ayrshire and Arran Complaints Department should be informed if any complaints arise regarding the project and the R&D Department must be copied into this correspondence.

The outcome and lessons learnt from complaints must be communicated to funders, sponsors and other partners associated with the project.

As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collated in line with NHS Scotland IT Security Policies, until the destruction of these data. Under no circumstances should personal data be stored on any unencrypted removable media e.g. laptop, USB or mobile device (for further information and guidance please contact the Information Governance Team based at Ailsa Hospital 01292 513693 or 513694).

If I can be of any further assistance please do not hesitate to contact me. On behalf of the department, I wish you every success with the project.

Yours sincerely

Dr Ken Ferguson Assistant Medical Director

c.c. Libby Prentice, SPONSOR contact
Lesley Douglas, Finance, Ailsa Hospital
Information Governance, Ailsa Hospital
Angela Cunningham, NHS Ayrshire & Arran
Cathy Kyle, NHS Ayrshire & Arran
Marisa Forte, NHS Ayrshire & Arran
Suzy O'Conner, University of Glasgow

www.nhsaaa.net

Appendix 15: Major Research Project Proposal

Title: A Qualitative Study of Fathers' Experiences of a Scottish

**Neonatal Intensive Care Unit.** 

<u>Abstract</u>

Background:

Heightened distress levels among parents of infants hospitalised in a

Neonatal Intensive Care Unit (NICU) and the promotion of Family Centred

Care (FCC) emphasise the need for health care professionals to

accurately understand parents' support needs.

Although fathers also experience distress in relation to the NICU,

traditionally, research has focused on mothers. Knowledge of paternal

needs has been restricted by studies investigating mothers and fathers

together, often with fewer number of fathers. Recent exploration into

fathers' personal experiences in the NICU has offered increased insight

into their needs. However conflicting findings (seemingly varying according

to country of residence) indicate a need for caution before generalising

results across different nations and their disparate health care systems.

As yet no investigation has been conducted into the experience of fathers

in Scotland. Therefore, to facilitate the provision of effective FCC for

fathers of preterm infants in a Scottish NICU, qualitative research is

required to gain an in-depth, bottom-up understanding of these fathers'

experiences.

<u>Aims:</u>

To explore fathers' experiences of having their preterm infants hospitalised

in a Scottish NICU, with a view to developing a clearer understanding of

their support needs.

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#### Methods:

This will be a cross-sectional study. An anticipated sample of 8 fathers will be invited to participate in semi-structured interviews about their experiences. Interpretative Phenomenological Analysis will be used to identify themes of support needs emerging from these interviews.

#### Applications:

It is hoped that information from this study will support the provision of effective FCC for fathers of infants in Scottish NICU's, and, in doing so, promote the wellbeing of parents and infants.

#### <u>Introduction</u>

Parents of infants admitted to a neonatal intensive care unit (NICU) experience significant distress including symptoms such as anxiety, depression, feelings of powerlessness, hopelessness and alienation, compared with parents' of full-term infants [1]. This distress has been associated with harmful long-term effects on family functioning [2] and impaired infant development [3].

Family Centred Care (FCC) is a philosophy of care intended to assist families with hospitalised infants to manage the stress, fear and altered parenting roles associated with this situation [4]. The importance of adopting a FCC approach in the NICU has been emphasised by research highlighting the association with FCC and reduced stress for both infants [5] and parents [6].

Therefore, it is essential that health care professionals working in the NICU understand the unique support needs of both parents in order to provide effective FFC to promote parent and infant wellbeing.

Traditionally, investigation of parental experiences in the NICU has focused on mothers [7,8,9,10,11,12]. This body of research indicates that mothers' support needs are consistent with the constructs of support identified in The Nurse Parent Support Model (NPSM) [13] (a) informational support - supportive communication and provision of information about the child and parental rights; (b) emotional support - listening, caring behaviours, and concern to help parents cope; (c)

parental esteem support - actions that respect, enhance, and support the parental role; and (d) caregiving support - the quality of care provided to the child. Although fathers also experience distress related to the NICU [14], most of what is known about their needs has come from investigations of mothers' and fathers' experiences simultaneously, often including a higher percentage of mothers [15,16,17]. This is unsatisfactory, particularly as research comparing mothers and fathers in the NICU indicate that their experiences differ in important ways. Tandberg, Sandtro, Vardal & Ronnestad [18] report that stress levels decrease between birth and discharge for mothers, but increase for fathers. Fathers also appear to experience greater stress in relation to managing their, often increased, responsibilities out with the NICU [19]. Differences have also been reported between maternal and paternal support needs; mothers desire increased responsibility in caring for their infant, while fathers want a balance between work and family life [20]. Therefore, it is insufficient to base our understanding of fathers' needs on an evidence base founded on research investigating mothers and fathers concurrently.

In recent years, research has aimed to better understand the unique experience of fathers' in the NICU [21,22,23,24,25,26]. While there are commonalities in the themes that have emerged across these studies (the need for information, emotional, and parental esteem support, (often to facilitate a feeling of control)), important differences have also emerged. The need described by fathers in Polman's [25] qualitative US based study, to return to work and provide financially for their infant conflicted with the need to be actively involved in their infants care, identified in a study of Swedish fathers [24]. These contradictory results are considered to reflect the variance in insurance and cost of health care between the two countries. Therefore, findings from existing research cannot be assumed to generalise across countries.

As yet no investigation has been conducted into the experience of fathers with preterm infants in a Scottish NICU. Therefore, qualitative research is required to gain an in-depth, bottom-up understanding of these fathers' experiences. This understanding will contribute to effective FCC by clarifying paternal support needs.

#### <u>Aims</u>

To facilitate the provision of effective FCC for fathers of preterm infants in Scottish NICU's, this study aims to use a qualitative approach to explore Scottish fathers' personal experiences of having their preterm infants hospitalised in a NICU, with a view to developing a clearer understanding of their support needs.

## Plan of Investigation:

## Participants & justification of sample size

A sample size of 8 is considered feasible and appropriate when using an Interpretative Phenomenological Analysis (IPA) approach [27] However, in accordance with Lyons and Coyle's [28] recommendations, to ensure that our area of interest is fully explored, recruitment will continue until thematic saturation is achieved. With a pool of approximately 30 fathers in Crosshouse Hospital's NICU at any one time, recruitment of this number is considered feasible.

#### Inclusion and Exclusion Criteria

As the budget for this investigation cannot cover the costs of a translator, participants must speak English to allow detailed accounts to be obtained about experiences [29]. Fathers of preterm infants, born  $\leq$  32 weeks gestation, and cared for in a Scottish NICU will be included in this study. As with previous research [22], fathers below the age of 18, and fathers of multiple births above twins, will be excluded from this study as they are considered to present with unique experiences. Similarly, fathers of infants who died, or are terminally ill will be excluded for the same reason.

## Recruitment Procedures

In accordance with IPA methodology, purposive homogeneous sampling will be used [29]. Fathers will be recruited from a convenience sample of parents of infants in Crosshouse Hospital's NICU at the time of recruitment. Nurses, who have been trained by the Principal Investigator (PI) to provide study information; specifically, participant information sheets and consent forms, will approach fathers who meet the inclusion criteria when their infant is approaching discharge. Fathers who provide their written consent via free postal return, will be contacted by the PI, who

will verify they meet with the inclusion criteria, and invite them to attend an interview. Interviews will be completed by the PI, a female trainee clinical psychologist, and be offered between the time of families' preparation for discharge and their three month follow-up neuro-developmental clinic. This interview timeframe was chosen following consultation with a member of the research team, who works closely with the target population. It was their opinion that, due to the work pressures on these fathers, participation may be easier for fathers if the interviews were available in conjunction with existing appointments, particularly as home visits are not possible.

#### Measures

IPA is particularly suitable for research investigating the uniqueness of an individual's experience as it aims to establish how meaning is created from their experience and how that meaning then affects them, both as an individual and in their cultural role [30]. Therefore, IPA is considered to be an appropriate qualitative approach for the purpose of this research.

Interviews will be used for data collection in this study as this method enables participants to offer detailed accounts of their experiences, and their thoughts and feelings about them [29]. In accordance with recommendations to facilitate the discussion of relevant topics [29], interview schedules have been developed for use with fathers. These schedules will be piloted and revised, if necessary, following the initial interviews.

#### Design

This will be a cross-sectional qualitative study; consisting of face-to-face interviews with participants.

## Research Procedures

Prior to recruitment, the individuals involved in participant recruitment (volunteers from among the neonatal nursing staff) will be provided with training from the PI on how to deliver study information and gather informed consent. Following receipt of consent, participants will be contacted by phone by the PI and invited to participate in interviews about their experiences in the NICU. Interviews will be offered to fathers at a time convenient to them, and will be available alongside their three-month neuro-developmental clinics to minimise any disruption to their daily lives.

The PI will be able to offer further information and answer any questions participants have during this phone contact. Interviews will be carried out by the PI, in a private room at Crosshouse Hospital, and are expected to last around an hour. Interviews will be semi-structured and based around the research questions. Before beginning, participants will be reminded of the topics likely to be raised and the time interviews will take, verbal consent to proceed will then be sought. Interviews will be carefully set up with the participants' comfort and wellbeing in mind; they will begin with an informal chat designed to put participants at ease and gathering of general demographic information before moving towards more potentially sensitive topics, and will be brought to a close with a more general and neutral discussion. Throughout the interviews, the PI will monitor the participants' emotional states. If the need for further support is identified, participants will be offered access to follow-up support from the psychological services embedded in the NICU.

#### Data Analysis

Interviews will be audio recorded and transcribed verbatim by the PI. The analytic process will begin with a detailed four-stage analysis of each participant's account [29].

- 1) <u>Reading and re-reading</u> to focus on, and emerse oneself within the individual's narrative.
- 2) <u>Initial noting</u> to engage with the text in detail (e.g. via commenting on the interviews descriptively, linguistically, and conceptually), and investigate possible meanings that emerge to move analysis towards conceptual interpretation.
- 3) <u>Developing emergent themes</u> and clustering them together by mapping the interrelationships, connections and patterns across notes taken during the initial noting.
- 4) <u>Searching for connections and emergent themes</u> in order to chart how the emerging themes fit together and highlight key aspects of participants accounts

This four-stage process will be repeated for each case before moving onto Step <u>5</u>) *looking for patterns across cases* and producing a graphic representation of the themes and sub-themes. This process facilitates the

generation of detailed descriptions of patterns of meanings, and reflections on shared experiences. As a measure of quality control two interviews will be re-analysed by a second member of the research team using the above process.

## **Practical Applications**

It is planned that information from this study will support the provision of effective FCC for fathers of infants in Scottish NICU's, and, in so doing, promote parent and infant wellbeing.

## Settings and Equipment

Interviews will take place in private rooms in Crosshouse Hospital.

#### **Health and Safety Issues**

Participant and Researcher Safety Issues

This study will be conducted in a private, safe environment where trained clinicians will be present.

## **Ethical Issues**

Ethical permission will be sought from the ethics committee, clinical psychology research and clinical governance committee and Ayrshire and Arran's Research and Development team. With regard to data protection, participant data will be stored securely in a locked filing cabinet in the Paediatric Psychology Department. The risk of harm through talking about sensitive issues has been considered and precautions taken; in addition to the provision of detailed study information (including possible outcomes and dissemination of the study, and the topics likely to be raised in interview), the trainee clinical psychologist conducting the interviews will monitor any effect on the participant and identify when discontinuation of the interview and/ or follow-up support would be appropriate. Participants considered in need of support will be offered access to the on site clinical psychology services.

Overall the possible risks of taking part in this study is considered by the research team to be outweighed by the potential benefits; the need of new

parents to share their feelings has been well documented [31], and fathers who have participated in similar research have reported finding the experience positive and validating [26].

## Timetable

April 2013: Proposal assessed

May-September 2013: Clinical & Research Governance/

R&D/ Application Ethics

October 2013- March 2014: Recruitment

October'13-Apri'14: Analysis
April-June 2014: Write-up

July 2014: Submit to university

September 2014: Viva

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