Exploring Parental Experiences of Neonatal Care: A Literature Review into Parental Experiences of Bereavement, Loss and Grief within the NICU & an IPA Analysis of Fathers' Experiences of Neonatal Care

Sarah Pratt

Thesis submitted in partial fulfilment of the requirements of Staffordshire University for the degree of Doctorate in Clinical Psychology

April 2025

Total word count: 17,931

(Excluding title pages, contents page, references, appendices and acknowledgements)

THESIS PORTFOLIO: CANDIDATE DECLARATION

Title of degree programme	Professional Doctorate in Clinical Psychology
Candidate name	Sarah Pratt
Registration number	22042136
Initial date of registration	September 2022

Declaration and signature of candidate
I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work. I confirm that the decision to submit this thesis is my own. I confirm that except where explicitly stated, the work has not been submitted for another academic award. I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis. Signed: S.Pratt Date: 30.04.25

Acknowledgements

I would like to extend my deepest thanks to all the fathers who so openly shared their stories with me, with whom this research would not have been possible without. Thank you to all the members of the neonatal community who took the time and effort to support with the recruitment and shaping of this research.

I would like to thank my research supervisor, Dr Gary Lee, for his invaluable guidance and support throughout this challenging process. To my clinical supervisor, Dr Nicola Anderton, a special thank you for not only instilling a passion for this topic within me but being part of the most incredible team of Psychologists who have and will continue to shape my professional career.

To my wonderful friends and family who have been on this journey with me, thank you for your continued support and belief in me, I appreciate and love you all so very much. To my DClin girls, I could not have wished to meet more amazing individuals on this journey, thank you for all the laughter, support and friendship. To Klaudia, from assistant psychologists to trainees together, we did it girl! Finding an absolute best friend for life in you is an honour.

To my niece and nephew, Evie and Rory, who always made me smile and gave me a hug when I needed it the most, thank you. To my wonderful partner, Joe. I can’t think of anyone else I would have rather had by my side during this journey, I feel incredibly lucky to have you. Your love and support are everything to me. It will always be you.

Finally, to my mum and dad, the people who have supported me through every endeavour and challenge in life, I am forever grateful to have the most

incredible, encouraging and caring parents. You both mean the absolute world to me. I hope I have made you proud. This is for you both.

Contents

Thesis Abstract

For partial fulfilment of the requirements of the Professional Doctorate in Clinical Psychology, this thesis broadly explores parental experiences of neonatal care.

Paper one presents a review of the literature into parental experiences of bereavement, loss and grief within the Neonatal Intensive Care Unit (NICU). This review explored qualitative papers depicting parental experiences of losing their infant within neonatal care. The findings of ten papers were critically appraised and thematically synthesised and two overarching themes were found: the immediate grief and grief over time. Findings should inform support offered to parents to ensure they are appropriately supported during this life event.

Paper two presents an empirical piece of research exploring fathers' experiences of Neonatal Care within England. Semi-structured interviews were conducted with eight participants, using Interpretative Phenomenological Analysis, transcripts were analysed to find three overarching themes: 'The emotional rollercoaster', the 'hidden not heard experience' and 'the people around you: help or hinder?'. Findings should inform service provision and support offered to fathers throughout their neonatal journey.

Paper three presents an executive summary, an accessible version of the research, described in paper two. The summary is for members of the public who have experienced a neonatal stay, professionals working within neonatal care and wider members of the public who wish to understand more about what it is like for parents in neonatal care. **Word count:** 227

Paper One: Literature Review

Parental experiences of Bereavement, Loss and Grief within the Neonatal Intensive Care Unit: A Literature Review and Thematic Synthesis

Target journal: Qualitative Health Research

This paper has been prepared in accordance with author guidelines for the above stated journal (Appendix M). Final formatting edits will be made prior to submission to the journal.

Word count: 7622

(Excluding Title Page, References and Appendices)

Abstract

The literature review aims to understand the parental experiences of bereavement, loss and grief within the NICU. The review explored how parents understand their grief and loss from the time of bereavement to life after bereavement and the implications for further research and clinical provision of support for parents.

A systematic search was carried out using EBSCOHost and PubMed databases, Google Scholar and hand searching, in March 2024. Articles were restricted to peer reviewed and written in English with no date limiters. Studies were reviewed based on the stated inclusion and exclusion criteria which resulted in 10 papers included in the review. All papers were qualitative and evaluated using the JBI Critical Appraisal for Qualitative research (JBI, 2015).

The included papers were reviewed and thematically synthesised. Two themes were included, the immediate grief and grief over time. Six subthemes were included: big emotions, communication, being a parent, growth after grief, grief doesn't go away and support.

A bereavement in the NICU is a life-changing experience for parents, from the psychological impact to the new outlook on life to a change in their personal identity. Findings should inform support offered to parents to ensure they are appropriately supported through this major event. The literature review depicts key research findings, implications for clinical practice, limitations of the review and future research directions in understanding bereavement, loss and grief within the NICU.

Keywords: NICU, neonatal, parent, grief, bereavement, loss

Introduction

Neonatal Intensive Care Units (NICUs) provide specialist care to babies and infants with serious medical and surgical conditions (Lakhani et al., 2023). NICUs are a unique medical care setting and are an emotionally intense environment for staff and families due to the high level of medical intervention taking place on vulnerable infants. These babies will be extremely premature, born before 28 weeks' gestation, or be very unwell after birth. Infants born this early will have underdeveloped organs and require life support (Kenner & Lott, 2014), for this reason, sadly death within the NICU is not uncommon with prematurity being the leading cause of death in neonates (World Health Organisation (WHO), 2023).

Parents of infants in the NICU fear their child may not survive and must juggle various demands such as caring for other children, recovering from the birth itself and occupational responsibilities (Clark et al., 2021). Therefore, parents of infants in the neonatal unit are facing extreme levels of stress and worry, even without losing their infant.

The death of a child, compared to other deaths of loved ones, has been evidenced to be more traumatic compared to loses of a spouse as one example, and can have a major impact on many areas of bereaved parents lives such as their relationships with one another, their personal life, their occupations and their emotional, psychological and physical wellbeing (Brooten et al.,2019). Understandably, the death of a baby often results in, complex and long-standing grief for parents, causing symptoms from emotional reactions such as hopelessness and anger to sleep loss and decreased energy (Laakso & Paunonen-Ilmonen., 2001). This is a unique type of grief as parents have had only a limited amount of time with their infants meaning few memories and connections have been made that would normally support the grieving process (Currie et al., 2019). Alongside this, parents have not been able to bring their infant home which is another loss for them in their journey of being a parent (Bennett et al., 2005), heightening their grief response. For parents in the NICU, loss is a recurrent theme. With some parents documenting they have never ‘got over’ the death of their infant (Christiansen et al., 2013), highlighting the significance of this event for parents throughout their whole lives. This puts them at risk of poor physical and psychological outcomes throughout their life and for many years after losing their infant (Lannen et al., 2008).

Research has shown that parents have higher mortality rates and psychiatric admissions than those who have not experienced the death of their infant (Currie et al., 2019). Research conducted by Youngblut et al. (2017) reviewed parents functioning months after the death of their infant in the NICU or paediatric intensive care unit. Results showed 35% of mothers and 30% of fathers reported clinical posttraumatic stress disorder.

Therefore, there is a need for research into the unique experiences of bereavement and grief of parents who have experienced a loss specifically in the NICU environment. The experience of neonatal death within NICUs specifically is important to understand as the NICU settings brings specific emotional challenges such as parents never bringing their child home after birth and the distress this causes. This review is needed to be able to inform support that NICUs provide to parents and their families during their NICU stay to ensure parents are appropriately and successfully supported during and after their infant’s death.

Rationale and Aims of the Review

There is no known literature reviews focused exclusively on parental experiences of neonatal bereavement within the NICU alone. Recent reviews completed in this area (Lakhani et al., 2023) have reviewed the needs of bereaved parents which has included practical considerations and recommendations for healthcare providers to guide their caregiving practices. This review looked at a range of qualitative and quantitative studies, combining parental experiences of bereavement, treatment withdrawal and end of life decision making and specific intervention reviews such as legacy making and breastfeeding. However, no review to our knowledge has reviewed the in-depth qualitative experiences only of parents who have lost a child on the NICU only and how they make sense of this experience, the bereavement, loss and grief. This previous review suggested a need for literature to be reviewed which considers parents who child has been alive and admitted to the NICU and then subsequently died, as the current literature review will do, as the experiences of those who have experienced a stillbirth or miscarriage or death at home after a NICU stay may be different to this occurring in the NICU (Lakhani et al., 2023).

This literature review aims to explore and understand parents’ qualitative experiences of bereavement, loss and grief, specifically from those who have lost an infant in the NICU. It also aims to inform ways that healthcare professionals respond to parents specifically in the NICU setting.

Methods

Scoping Searches

An initial search of Google Scholar, the PROSPERO international register for systematic reviews, and the Cochrane Library, for existing systematic reviews on the topic yielded no results. Preliminary literature searches of Google Scholar were reviewed to understand how bereavements are documented within the neonatal context to inform the search terms for the review. Relevant literature reported deaths within the NICU to be referred to as ‘death’ or ‘loss’ or ‘bereavement’, used interchangeably with ‘neonatal’ and ‘infant’. Thus, the literature review will use combinations of these terms to search for relevant papers.

Search Strategy

A search for relevant literature was conducted during March 2024 using the following databases: PubMed, EBSCOHost (consisting of the following databases: PsycINFO, PsycArticles, CINAHL, MEDLINE, SPORTDiscus). The search terms used related to both neonatal, death and parents. Initially, searches isolated the terms as ‘death’ or ‘loss’ however this retrieved many irrelevant articles for example looking at death in any setting. Therefore, terms to refer to ‘death’ and ‘infant’ were combined to make the following key search terms, boolean operators, ‘AND’ and ‘OR’ were used in the search: ("neonatal loss" OR "neonatal death" OR "infant death" OR "infant loss" OR "bereavement") AND ("parents" OR "parental") AND ("NICU" OR "neonatal intensive care unit"). No date limiters were applied to the search to ensure all potential studies were considered for inclusion. The publication dates of studies included in the review, ranged from 1991-2023, no qualifying studies were published in 2024 before the search was conducted. All the articles were qualitative studies. Within each database, articles were identified that included the key search terms in their title or abstract. All-peer reviewed papers were reviewed. The reference lists of all the included studies were hand searched for any relevant articles. Two further studies were found that met the inclusion criteria. Due to Lakhani et al, (2023) recent review with a similar focus, the reference list of this systematic review was hand searched for relevant papers to ensure no relevant papers were missed. Two further studies were found that met the inclusion criteria. This enables the current review to build on existing reviews in the field.

Inclusion criteria

(1) Study sample were parents only.
(2) Study adopted a qualitative methodology to look at experiences.
(3) Study focused on or included the experiences of a bereavement, loss or grief only, NOT end of life care, decision making or experiences of events before infants' actual death only.
(4) Studies that looked at deaths within the Neonatal Intensive Care Unit setting only, not deaths after a NICU stay, stillbirths or miscarriages.
(5) Peer-reviewed articles.
(6) Studies written in English. Due to the review being part of a student doctoral thesis, no financial support was available to employ an interpreter to translate any relevant articles not published in English.

Exclusion Criteria

(1) Papers that focused on reviewing support interventions offered to parents during their NICU stay.
(2) Systematic reviews, information articles, essays or meta-analyses.

Titles and abstracts were screened against the eligibility criteria by the named author alone. If there was any uncertainty about the suitability of a paper based on the title and abstract alone, the full text of the paper was screened, ensuring no relevant papers were dismissed incorrectly.

Publication Bias

Publication bias in qualitative research can exist when studies that do not show clear or striking findings are not published (Petticrew et al., 2008). To mitigate the impact of publication bias, grey literature was searched using ProQuest for possibly relevant unpublished literature. No further papers were identified in this search. Google Scholar was also reviewed. Due to a high volume of results on Google Scholar, the first 200 results were reviewed only due to recommendations by Haddaway and colleagues (2015), to examine the first 200-300 results only for a literature review. One relevant paper was found through this method however the paper was a published article. Therefore, no grey literature has been used in the present review.

Data Extraction

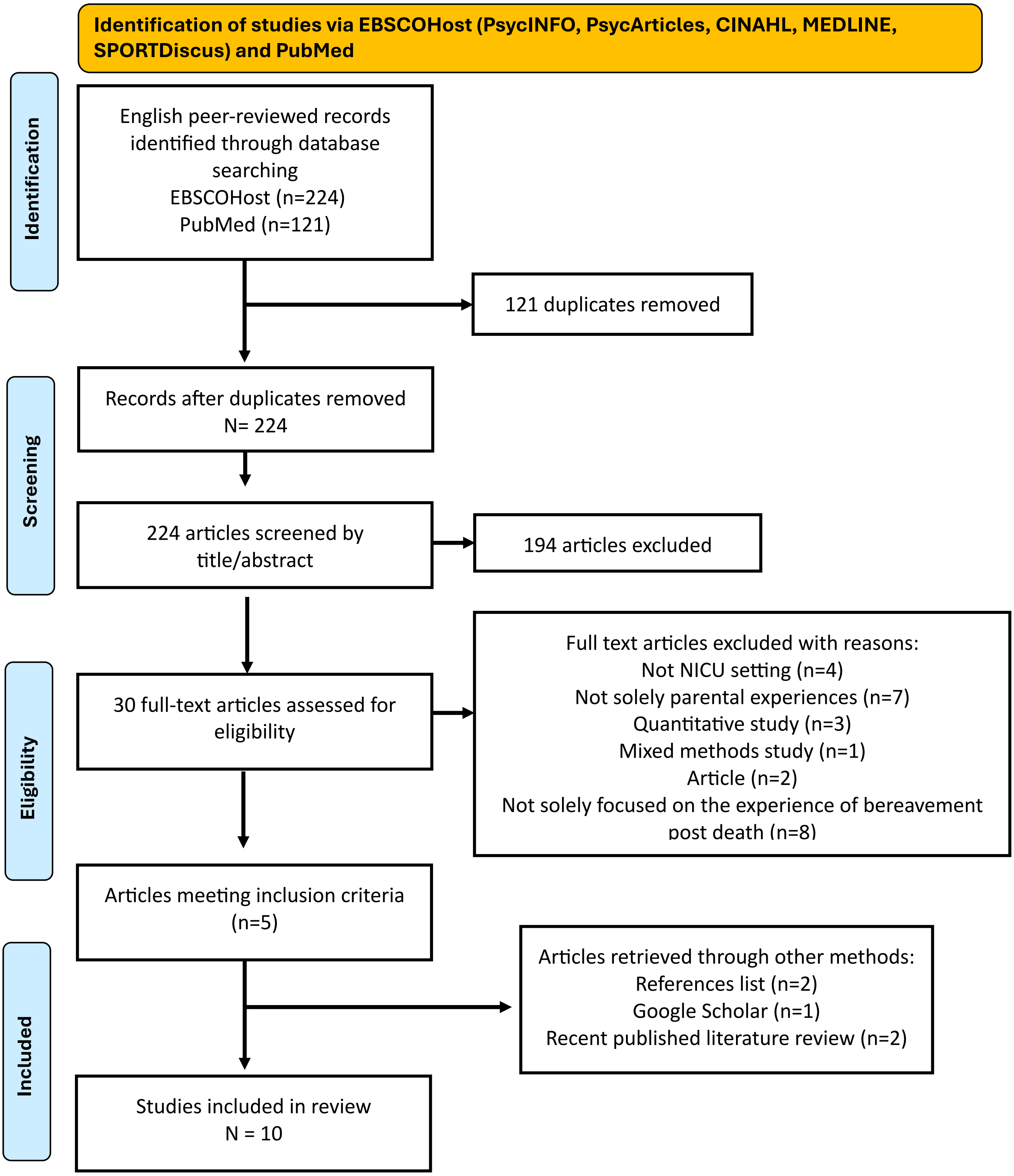
The following data were extracted from each study: author, year, aims, sample, study design and analysis, key findings, strengths and limitations. Key quotes from authors findings and discussions were recorded in a document.

Search Results

The initial search yielded 345 results, 121 were identified as duplicates and removed, leaving 224 papers to review. The titles and abstracts of the remaining papers were screened and if relevant, the full texts were reviewed, 194 articles were excluded at this point. The full texts of the remaining 30 papers were reviewed by one author in line with the eligibility criteria and a further 25 papers were excluded, leaving five papers to be included in the literature review. Two papers that were identified by hand search of reference lists, one paper identified via Google Scholar and two papers retrieved from a recent relevant literature review were included in the current literature review resulting in 10 papers being included in the literature review. Figure 1 displays this process evidencing reasons for the exclusion of papers.

Figure 1

PRISMA Flow Diagram (2021)



Quality Assessment

To quality assess the studies consistently, one critical appraisal tool was utilised. The Joanna Briggs Critical Appraisal Checklist for Qualitative Research (JBI, 2015). The JBI critical appraisal checklist is a 10-item tool designed to assess the methodological quality of a study and to determine the chance of bias being present in the study (JBI, 2015). The checklist was chosen as it focuses specifically on the appraisal of qualitative studies making it appropriate for this review which includes qualitative papers only. Quality assessment of the studies was supplemented by using the critical appraisal checklist to find strengths and limitations of the research, these were then extracted and noted in the review table in Appendix A.

Each item on the checklist is answered ‘Yes’, ‘No’ ‘Unclear’ or ‘Not applicable’. Articles were given 1 point if the criterion was fully met and 0 points if the criterion was not met or of it was unclear if the criterion had been met as the author could not confidently state that the paper passed that criterion of the appraisal tool to give it a numerical value above 0 (Appendix B).

Data synthesis and analysis

To synthesise the results from the selected papers, a thematic synthesis was conducted following the approach by Thomas and Harden (2008). This synthesis was chosen as Thomas and Harden (2008) proposes that thematic synthesis is used when the review is concerned with people’s experiences, attitudes or views and due to the qualitative nature of the current reviews’ papers. The aims of the review are to understand parental qualitative experiences which a thematic synthesis aims to do as opposed to other types of synthesis such as a narrative synthesis which is used to combine qualitative and quantitative data. Data from the ‘findings and discussion’ section of each paper was coded line-by-line. A primarily inductive approach was taken to generate codes. A pragmatic approach was taken to group codes together to generate descriptive themes based on similarities across papers. This included keeping a log of how many times and in which studies, similar codes appeared. To 'go beyond the original findings' (Thomas & Harden, 2008), codes were then used to construct analytic themes.

Reflexivity

It is important for the author to reflect on their own biases and experiences as reflexivity is an important part of the quality assessment of qualitative studies. The author has experience working in NICUs so expected to find a theme depicting that bereavement within the NICU provokes strong emotions. To ensure a rigorous review process, the author aimed to separate their experiences from factual results by using bracketing, thusby re-checking the accuracy of their interpretations of themes throughout the synthesis.

Results

Overview of Included Studies

The main characteristics of studies included in the review are shown in Table 1. All 10 papers included in the review were peer-reviewed articles. Further quality assessment identifying strengths and limitations of the studies can be found in Appendix A.

Table 1

Summary table of study characteristics

Author (s) & Year	Aim	Sample	Research Design	Key Findings	Critical Appraisal Score
Aagaard et al.,2016	To generate a deeper understanding of parent's experiences of losing one twin in the NICU.	Parents of 1 infant.	Qualitative. Interview. Thematic analysis.	3 major themes: difficulties understanding the verbal and cultural discourse within the NICU, relation between nursing staff and parents & the struggle to become an active parent.	6
Abdel Razeq & Al-Gamal, 2018	(1) provide an in-depth and rich description of the living experience of the be- reaved mothers during the time after	12 mothers. NICUs in Jordan.	Qualitative. Interviews. Phenomenological approach.	3 major themes: longing and grieving, the adaptive work of coping and moving forward but with a scar.	8

	losing newborns at the NICU and (2) analyze how bereaved mothers recon- struct the meaning of losing a newborn infant in the NICU.				
Abdel Razeq & Al-Gamal, 2021	To understand the lived experience of mothers surrounding the time of being informed of neonatal deaths in intensive care units.	12 mothers. 2 NICU units in Jordan	Qualitative. Semi-structured interviews. Interpretative Phenomenology.	3 major themes: 1) Minimise the hurt, which described how mothers intuited overprotection by their families while the news was conveyed directly to them; 2) The striking reality of death, which captured mothers’ distressing experiences while realising the loss of their neonates and 3)	9

				Farewell my baby, which accentuated mothers’ needs and experiences while neonates’ bodies were honoured and prepared for burial.	
Armentrout, 2007	To address parent’s perspectives about their infant’s death and their everyday lives after their infant’s death.	15 parents, 4 couples and 7 mothers Single online support group.	Qualitative, Interviews, Grounded Theory	Main themes: Facing the decision, Life goes on and Lives forever changed. Core variable: The Process of Holding a Place: parents’ Lives Following the Removal of Infant Life Support.	8
Azeez etal.,2022	Explore fathers’ bereavement experiences following neonatal death	10 fathers	Qualitative. Interviews. Descriptive, exploratory methodology.	3 overarching themes: 1) A complicated grief experiences: Neonatal death is highly emotional. 2) Grief is multidimensional. 3) Sense of injustice.	9

			Thematic analysis.		
Clark etal., 2021	To examine parent perceptions of emotional, social, occupational, familial and physical impacts of infants death and to provide insight into the psychosocial needs of parents.	29 mothers and 16 fathers. 1 representing 30 infants Midwestern NICU.	Qualitative. Interviews. Content analysis. Single centre study.	5 major themes: (a) negative effects, (b) positive effects, (c) no significant change, (d) coping, and (e) grief trajectory. Subthemes included the effects on parents' lives across several domains (i.e., emotional, social, physical, and occupational functioning).	7
Currie etal., 2019	To explore parent bereavement and coping experiences after infant death in the NICU.	10 parents of 8 infants. 7 mothers, 3 fathers. All from 1 NICU in US.	Qualitative. Descriptive. Interviews. Content analysis.	2 major themes: living with loss and coping with grief over time.	8

Geetanjli et al., 2012	To determine and assess the loss and grief response, and perceived needs of parents who are having their newborns in neonatal care units.	16 parents of 9 babies (7 singletons and one twin).	Qualitative. Interviews. Hermeneutic Phenomenology. Single centre study.	The study found that the loss of parents was ‘Anticipated’ and ‘Actual’ related to separation from baby, loss of baby etc. Grief responses were ‘psychological’ e.g. tension, anger, crying, denial, bargaining, confusion, preoccupation, and ‘physical’ e.g. loss of appetite, sleep etc. The perceived needs were mainly, to have a ‘Friendly visiting policy’, ‘Proper information’ and ‘Communication’.	7
Kimble, 1991	To describe the human experience of fathers whose infants have died in an NICU and to compare their reactions	8 fathers.	Qualitative. Interviews. Descriptive Study.	Symptoms of grief: 1. Feelings 2. Physical responses 3. Reactions and behaviours.	3

	to those of grieving mothers.				
Lakhani et al., 2023	To elicit and represent NICU parents' stories of goals of care decision-making and experiences that support their bereavement.	7 parents, 5 mothers and 2 fathers. Canadian NICU	Qualitative, Narrative Design, Interviews	Main themes: 1. Parents recounted stories of the time they had with their children. 2. Parents shared stories of the Healthcare Providers doing what they could and should do for their children. 3. Parents told stories of living with uncertainty, ambiguity and indecision. 4. Parents shared stories that expressed values of caring. 5. Parents talked about what their child's life was like. 6. Parents shared stories of living with loss.	8

Quality Appraisal

The JBI-Critical Appraisal Checklist for Qualitative Research scores are shown in Appendix C. The current review considered a higher score on the checklist to indicate a high level of research rigour in the study.

Sampling and Recruitment

Studies used purposive sampling methods whereby potential participants were directly approached via a range of methods e.g. letter, face to face or email based on medical records, presence at a local support group or bereavement programs. Purposive sampling is useful in identifying individuals that have knowledge about the phenomenon of interest however it can increase the risk of research bias in a study as the sampling relies on the researcher's opinions and judgements about participants suitability for the research (Cresswell & Plano Clark, 2011).

All studies recruited from one geographical location, some from just one isolated NICU (Lakhani et al., 2023; Abdel- Razeq & Al-Gamal, 2021; Currie et al., 2019; Aagaard et al., 2016). This results in a lack of generalisability of the findings of the papers as results have been gathered in a particular area. Experiences may be different outside of that geographical area due to variation in healthcare provision, support or cultural beliefs for example. Research could benefit from including participants from more than one geographical area within an individual study to be able to compare experiences across cultures.

Sample sizes of the papers ranged from two to 45 individual parents, representing 85 mothers and 52 fathers across all studies. Across the studies, those that reported the number of infants that this represented, one paper represented one infant (Aagaard, 2016) however this paper was a case study, so this was appropriate sampling. The other papers ranged from five to 30 babies who died in the NICU.

Methodology

Most of the studies included in the review chose appropriate research methodology based on the philosophical perspective they had adopted to carry out their study (Lakhani et al., 2023; Armentrout, 2007; Abdel Razeq & Al-Gamal, 2021; Currie et al., 2019; Geetanjli et al., 2012; Abdel-Razeq & Al-Gamal, 2018; Kimble 1991 & Azeez et al., 2022). However, with two studies (Clark et al., 2021; Aagaard, 2016), it was unclear whether the research methodology supported the philosophical perspective which makes it hard to understand if the paper was able to research what it set out to understand. Some common strengths across papers included congruity between the research methodology and the methods to collect data and the research methodology and analysis of data. Studies chose qualitative ways to collect data such as interviews and analysed data using qualitative methods including grounded theory (Armentrout, 2007), interpretative phenomenological analysis (Abdel-Razeq & Al-Gamal, 2021), thematic analysis (Aagaard et al., 2016) and narrative analysis (Lakhani et al., 2023), all appropriate analytical methods for a qualitative paper. Although Kimble (1991) did not explicitly state the method used for analysis, therefore the congruity between analysis and research methodology could not be accurately assessed. This may mean results have been missed or misunderstood in this paper.

Ethics

Another common strength across papers is that there were clear evidence of ethical approval and ethical considerations within each study. It is vital that ethical considerations are made in qualitative research as the research gathers personal views, opinions and experiences where participants can be identified, feel vulnerable and raise strong emotions (Laryeafio & Ogbewe, 2023), therefore ethical steps need to be in place to protect these individuals from harm. Within qualitative research, factors are present such as the power between participants and researcher, therefore a participant needs to feel safe to want to take part in the interview which should be considered within ethical approvals (Orb et al., 2001). Only one paper did not explicitly state their ethical approval or considerations (Kimble, 1991) which questions the morality of the paper, considering the focus of the research is on a highly emotional topic.

Analysis

All papers were successful in including quotes from participants to support the interpretations of data made apart from Kimble (1991) which included no clear quotes to represent the voices of participants accurately. Additionally, some papers stated they had multiple authors contribute to the analysis and meetings held to discuss data which helped to mitigate against researcher bias and ensure data being reported was accurate increasing the rigour of the research findings. Some also gave participants chance to review findings to check their accuracy (Lakhani et al., 2023; Abdel-Razeq & Al-Gamal, 2021; Currie et al., 2019; Aagaard et al., 2016; Geetanjli et al., 2012; Abdel-Razeq & Al-Gamal, 2018).

Researcher Stance

A common factor which had an impact on the overall scores of papers was that most papers did not locate the researcher culturally and theoretically. Only one paper (Abdel-Razeq & Al-Gamal, 2021) did both with two papers locating the research culturally only (Geetanjli et al., 2012 & Abdel-Razeq & Al-Gamal, 2018). Without this knowledge, it is difficult to know how the researchers' beliefs and values have influenced the study and ultimately affected the results reported. The researcher plays a substantial role in the research process; therefore, it is important for a study to declare the researchers' culture and theoretical stance to be able to test the rigour and bias of the research. Similarly, few studies included a statement highlighting the influence of the researcher on the research. An important component of qualitative research is the researcher's ability to reflect on their position and context. 'Postitionality' reflects the position that a researcher has chosen to adopt within a given study, influencing how the research is conducted and its results (Rowe, 2014). Without reflexivity and a statement around this, research may not be conducted ethically (Holmes, 2020). Studies that included a reflexivity statement were deemed to be of higher quality (Azeez et al., 2022).

Kimble (1991) received a poor score of three, after consideration with supervisors, the study was included due to the limited amount of research in this area and the need for a literature review to be conducted. The study provided limited details around the position of the researcher, ethical considerations, the voices of the participants and the methods of analysis and interpretation of the data. This resulted in numerous 'No' and 'Unclear' being chosen for items on the checklist, resulting in a low critical appraisal score and deemed to be a lower quality paper. These limitations restrict the extent to which results can be accepted and generalised from this paper with a low score representing a low amount of rigour in the research.

Synthesis of Findings

The thematic synthesis of results generated six descriptive themes: big emotions, communication, being a parent, growth after grief, grief doesn't go away and support. The descriptive themes were considered to produce two analytical themes to 'go beyond the original findings'. The analytic themes were the immediate grief and grief over time (Table 2). A theme was only considered a theme if it was included in five or more papers to ensure it reflected the synthesis of findings. Themes were presented in chronological order of the parents' journey through NICU and the frequency of times the individual theme was reported.

Table 2

Themes and subthemes generated from the studies.

Theme		Aagard et al., 2016	Abdel Razeq & Al-Gamal, 2018	Abdel Razeq & Al-Gamal, 2021	Armentrout, 2007	Azeez et al., 2022	Clark et al., 2021	Currie et al., 2019	Geetanjli et al., 2012	Kimble, 1991	Lakhani et al., 2023
The immediate grief	Big emotions		X	X		X	X	X	X	X	X
	Being a parent	X		X	X	X	X	X	X		X
	Communication	X				X		X	X		X

Grief over time	Support	X		X	X	X	X			X
	Grief doesn’t go away	X		X	X	X	X			X
	Growth after grief	X			X	X	X		X	X

The Immediate Grief

Big emotions

This subtheme was supported by eight studies. Difficult emotions were frequently reported by parents who had faced a bereavement on the NICU, such as deep sadness, anger and anxiety (Geetanjli et al., 2021; Abdel-Razeq & Al-Gamal, 2021; Azeez et al., 2022). One study reported psychological reactions like fear/sadness/ anxiety were commonly related to survival of baby (Geetanjli et al., 2012) and that mothers perceived learning about the loss as very hard and extremely painful (Abdel-Razeq & Al- Gamal, 2021).

Parents reported feelings of numbness, shock and disbelief. Parents felt they had little preparation for their death or time to understand what was happening in the NICU which added to their intense feelings of shock and disbelief upon their infant's death (Azeez et al., 2022). One parent reported: 'I just didn't know what was going on. I just, I just kept saying it and it was like why am I- I was so confused, and it was exhausting' (Azeez et al., 2022 p. 1449). Parents then have the realisation that they will be leaving the hospital without their newborn as they had hoped and suddenly, visiting the infant in the NICU is no longer part of their life (Lakhani et al., 2023). One parent reflected: 'After she had passed away, I didn't know what was next. I have no idea what happens now.. Do we just go out?' (Lakhani et al., 2023 p. 1286).

Parents reported an emotional impact on their physical wellbeing such as sleep disturbances, pain and eating difficulties (Geetanjli et al., 2012). Parents attributed these symptoms to the intense emotions they were experiencing after their baby died, showing the traumatic nature of a bereavement in the NICU (Clark et al., 2021). One parent reported: 'It made me depressed. I'd go 3 days at a time without eating… obviously she wasn't coming home so it's like, what do I have left'? (Clark et al., 2021 p. 265).

Being a parent

This subtheme was supported by seven studies, identifying that 'being a parent' was important to the processing of the bereavement and grief. Parents reported wanting to be able to be involved in 'normal parenting' activities such as bathing and holding their infant before they died. By having this time together, parents felt they had the time to get to know their child and for their child to know their family, (Armentrout, 2007). One parent reflected: 'I think it's important to allow yourself to be a parent before you let go of your baby, to change their diaper… and be a parent to 'em… because that is something you will cherish for the rest of your life' (Armentrout, 2007 p. 7).

Some parents felt it difficult to build this bond. Parents reported it was at times hard to be an 'active parent' on the NICU due to the technical equipment providing a barrier to connection with their infant, affecting their confidence in being a parent to their infant and becoming insecure when they could hold their infant (Aagaard et al., 2016).

Parents felt memories made with their infants helped process their bereavement. Parents wanted to be physically close to their infant when they died and felt it was important to be together as a family when they passed. One study reported that parents wanted to be able to watch over their children, hold their children, feed their children, read to their children and be present (Lakhani et al., 2023).

Parents felt it was important for the infant to be part of their whole family's life and always remain a part of their family's life, even after their passing. One parent stated: ‘Our daughter points to his picture… she will always know that’s her brother and he may not be here physically but he’s always going to be a part of our lives’ (Armentrout, 2007 p. 8).

Parents reported feeling comfort in the memories they had made with their infant and the time they had to be able to build a bond and do things together. The importance of bonding for parents and infant and a need to ensure as much time together is spent as possible to help the parent in their grieving process is evident.

Communication

This subtheme was supported by five studies and related to parents highlighting that communication was important to them. Parents expressed that they wanted to know what had led to their infants’ death. They felt it was important to know nothing was being hidden from them (Azeez et al., 2022). Parents wanted information explained clearly to them to help their understanding and ease anxieties. One study concluded that ‘Staff must strive to understand the parents, needs and concerns and provide them with understandable information’ (Aagaard et al., 2016 p. 157).

Parents wanted to feel heard in the NICU and felt that the care the baby was receiving in the NICU reflected their beliefs and wishes. Consideration needed to be given to cultural beliefs around care and death (Lakhani et al., 2023). One parent reported: ‘A Muslim doctor told me to take off oxygen from my son… but in my beliefs, doctors come to save people, they don’t try to give up on the patient’s life’ (Lakhani et al., 2023 p. 1284).

Some parents reported some communication from friends and family that was intended to be helpful, but they found it hurtful. Some parents felt that people were pretending to understand how they felt and then did not give them the responses they wanted which was upsetting (Currie et al., 2019). One parent reflected: ‘It still irritates me to this day when people say ‘I know how you feel’ because they don’t (Currie et al., 2019 p. 337) and ‘I had a lot of friends who would just never bring it up and just act, like you know, nothing ever happened, we were never pregnant, baby was never born, which hurts (Azeez et al., 2022 p. 1450).

However, some studies reported that parents acknowledged that people do attempt to be sympathetic and can appreciate infant loss is a difficult subject to broach even though parents felt isolated from their support networks due to difficult communication (Currie et al., 2019).

Grief over Time

Support

This theme was supported by six studies and depicted the role of varying types of support, such as from friends, family, spiritual and professional that had an impact upon the parents following their loss. One paper (Lakhani et al., 2023) described parents’ stories of seeking support from bereavement counsellors as useful in being able to live with grief. One parent reported: ‘What was really better for us was bereavement counselling… helped us understand the way that each other was grieving’ (Lakhani et al., 2023 p. 1286).

Another area of support that was useful to parents was finding support from their spouses. This may be associated to them going through the same event so could begin to understand each other’s feelings and respect each other’s feelings (Kimble, 1991). One study on fathers only reported: “Fathers reported feeling ‘closer’ and ‘stronger’ in their relationships with their spouses… one father attributed this new strength to ‘having gone through hell together” (Kimble, 1991).

However, findings also showed conflict between spouses due to them having different ways of grieving and understanding their loss (Currie et al., 2019). One parent reported: ‘I was expecting more support from him, but I think he was incapable of giving that support’ (Currie et al., 2019 p. 337).

Spirituality was a source of support across many papers. Parents reported using spirituality to find a meaning for their infants’ death and find a reason for their loss ,(Abdel-Razeq & Al-Gamal, 2018 & Abdel-Razeq & Al-Gamal, 2021). One parent stated: ‘God gave them to us, and He is the One who took them from us too… It is all God’s will’ (Abdel-Razeq & Al- Gamal 2018 p. 141).

This theme outlines the range of support parents lean to when faced with an unthinkable event such as the loss of an infant. The theme goes on to represent that it is a personal choice what support will be most useful for that individual.

Grief doesn’t go away

This subtheme reflects the finding that the loss of an infant and the grief associated, forever stays with the parents (Currie et al., 2019). It is supported by six studies. Parents spoke about the difficulties of ‘getting over’ losing an infant. With the experience of the NICU living on in parents’ memories (Clark et al., 2021). One parent reported: ‘You move on but you never get over it (Armentrout, 2007 p. 8). Just always there… but it never goes away… it just never goes away’ (Armentrout, 2007 p. 8) and ‘I think of him so much. I remain shocked and wondering. All that happened was a tape that keeps playing in my head’ (Abdel-Razeq & Al-Gamal, 2018 p. 140).

This theme depicts that losing an infant in the NICU stays with parents in some way for a long time, parents continually spoke across papers of how they may learn to live with grief, but it is never forgotten (Currie et al., 2019; Lakhani et al., 2023; Clark et al., 202; Azeez et al., 2022; Abdel-Razeq & Al-Gamal; 2018; Armentrout, 2007).

Growth after grief

The impact of grief was long-lasting for parents. Parents reported their identity to have changed and never feel that they will be the same again (Azeez et al., 2022; Currie et al., 2019). This theme reflects the positive change parents experienced following the loss of their infant and is supported by five studies. One parent reported: 'There's a really clear cut-line between who I was before and who I am now, so it's changed pretty much everything about me from how I look at life and how I approach things and how I sort priorities' (Azeez et al., 2022 p. 1448) and another stated: 'I think I matured a little bit. Became more stronger' (Currie et al., 2019 p. 336).

Some parents described feeling more grateful for life and enjoying each day of their life more (Clark et al., 2021) with one reflecting: 'On the whole, it's been positive. I feel more gratitude. I really just try to focus on what's important, and you know value time with family and value time with others' (Clark et al., 2021 p. 226). Parents described a change in priorities in life with some taking time to commemorate their child such as walks to raise money for diseases and illnesses charities or providing peer support and counselling to other parents and families (Armentrout, 2007). One study concluded that 'Participants discovered themselves involved in various activities because of having an infant died… they all wanted to do something to commemorate their child's life' (Armentrout, 2007 p. 10).

Throughout this theme, it is highlighted that the loss of an infant is a life changing event, many experienced a change to their identity, (Currie et al., 2019; Armentrout, 2007; Azzez et al., 2022; Clark et al., 2021). It appears grief provides a space for personal growth and development with new outlooks and appreciation of life (Clark et al., 2021).

Discussion

The aim of this review was to synthesise the experiences of parents who have lost an infant on a NICU. To the best of our knowledge, this review is the first of its kind that looked only at the qualitative experiences of losing an infant specifically in the location of the NICU from the parents' viewpoint only. This review focused on understanding, in depth, parents' experiences of what it is like to lose an infant in the very early stages of their life.

This review demonstrated that the grief of losing an infant on the NICU is forever present for most parents. Parents often described 'moving on but never forgetting' their infant. This review categorises the experiences of bereavement, loss and grief in parents into the grief felt immediately after the death and the grief felt over time to depict the journey of grief for parents and how this changes over time. With awareness of how parents experience their bereavement and grief over a period of time, this may influence the support offered to parents throughout their journey.

Considering the immediate grief for parents, this review depicted the strong range of emotions felt by parents from sadness to anger. A previous systematic review looking at grief following a bereavement in the NICU and stillbirth, from the viewpoint of fathers only, yielded similar results to the current review (Jones et al., 2019). This review depicted that fathers could experience a range of psychological impacts as the event of losing an infant pre-birth or post-birth is regarded as highly traumatic. Previous research has evidenced that stillbirth is associated with depression, anxiety disorder, social phobia, agoraphobia, anger and guilt (Burden et al., 2016), further supporting the current reviews findings of the psychological impact of loss in the NICU. An important subtheme in this research was the reporting by parents of the need for effective and clear communication from healthcare staff on the NICU. Parents reported this to help their grieving process and understanding and acceptance of their bereavement. This important finding for healthcare provision has previously been reported in research following a parental death, evidencing the need for open and honest communication helps children to cope when they have lost a parent (Wray et al., 2022).

This literature review has demonstrated the post-traumatic growth following grief. Parents reflected a sense of finding a new meaning in life, not taking life for granted, becoming stronger and appreciating time spent with their family more after losing their infant (Clark et al., 2021; Armentrout, 2007; Azeez et al., 2022; Currie et al., 2019). Previous research into parents who have had a child hospitalised in the NICU has shown posttraumatic growth in the NICU following the loss of a baby (Barr, 2011). This has been attributed to factors including existential emotions, coping strategies, shame, positive reappraisal, fear of death and guilt (Barr, 2011). Regardless of this seemingly positive change, this literature review evidenced that the grief is everlasting for parents with many still living with the negative impact and difficulties of losing a baby.

A previous unpublished review by Reuvers (2018) on parental loss and grief in the NICU found similar themes to the current review, support, not knowing what to expect, hospital practices, communication and coming through grief. The results support the current reviews findings into the importance of communication and support for families and how life looks after grief.

Limitations of The Review

This literature review had one reviewer assessing papers and findings only. Research recommends dual independent reviewing of papers by two individual reviewers to improve reliability and transparency of results (Stoll et al., 2019), however this is resource heavy and for this literature review, another reviewer was not appropriate. Using a qualitative method of synthesis is open to bias as is any qualitative research. The author had professional experience of the topic and setting reviewed so may have synthesised results to support themes they believe to exist. The author used reflexivity whilst conducting the review to separate their views from the factual findings of the studies reviewed to increase the validity of the synthesis.

No unpublished grey literature was included in the review which is a limitation. It can be useful to include grey literature in reviews as it can highlight negative or null results in studies which otherwise may be ignored due to publication bias (Hartling, 2017). By including grey literature, it helps not only reduce publication bias but also ensure a balanced picture of the evidence is available is included in the review which increases the reviews comprehensiveness (Paez, 2017).

The quality of the 10 included papers in the review was mixed, with the position of the researcher culturally and theoretically and the impact the researcher may have had on the research, not explicitly stated across all papers. This raises concerns about bias across some studies. In qualitative research reflexivity and positionality are important in reducing the chance of bias and ultimately ensuring a high level of rigour in the research. However, most studies conducted research ethically and used appropriate methodology to yield relevant results to their research question and aims.

Implications of the findings

A previous review by Lakhani et al (2023) into the considerations for practice in supporting parents in the NICU evidenced the need to understand the unique NICU bereavement experiences of each individual to provide effective support. The following table is a summary of practical recommendations that should be employed in clinical settings based on the themes found in this review (Table 4).

Table 4

Summary of Practice Recommendations

Theme	Practice Recommendations
Big emotions	The psychological impact of the NICU should be considered and the impact this can have on physical health. Emotional support should be routinely offered to parents as soon as their stay on the NICU begins whether this take the form of psychological therapy or more informal methods such as peer support and groups.
Being a parent	Parents should be allowed to have as much autonomy over their involvement with their baby as is medically safe. Parents should be actively encouraged to bond and make memories with their baby, staff should facilitate this.
Communication	Information should be communicated to parents in an accessible manner and time given for parents to answer questions. Parents should be considered throughout their infants NICU stay. Cultural humility should be considered when making and communicating decisions around care.

Support	Staff should be accessible to parents for emotional support. Staff should encourage parents to seek support from spouses, friends and family if they wish. Support needs should be considered on an individual basis.
Grief doesn’t go away	Care should look to be provided post NICU and long-term if necessary to help parents process their grief.
Growth after grief	It may be useful to have psychological support offered to parents over a long time period to support parents in their transition through grief.

Future research should endeavour to explore the experiences of parents from various cultures and geographical locations within one study. Generally, there was a consensus across studies of the experiences of parents however there was some variability between studies from different cultures. Mothers in Jordan (Abdel-Razeq & Al-Gamal, 2018) reported a prominent theme of spirituality which other papers did not. Research into this area may benefit from being able to compare and contrast the experiences and needs of parents from different cultures within a singular study to improve the individualisation and tailoring of care. Cultural and belief considerations have been evidenced to be an important consideration in the care of an infant on the NICU (Lakhani et al., 2023).

Conclusions

Findings have highlighted that parents may require different support at different stages of their journey from support for the initial psychological trauma to processing the grief and a new life without their child. The review has identified a need for healthcare staff to communicate clearly with parents, offer parents time and support to bond and make memories with their infant. Support offered to parents from professionals, friends, family and spouses returned conflicting views so should be considered on an individual basis. Spirituality was reported to be important for some parents. This review like a recent review (Lakhani et al., 2023) evidences a need for further research into the cultural differences in support needs of parents to ensure support is tailored and appropriate for that individual.

References

Aagaard, H., Storm, I., & Klitgaard, J. (2016). Losing one twin in the NICU – A case study of the parental experience. *Journal of Neonatal Nursing, 22*, 153-158.

Abdel Razeq, N. M., & Al-Gamal, E. (2018). Maternal Bereavement: Mothers' Lived Experience of Losing a Newborn Infant in Jordan. Journal of hospice and palliative nursing : *JHPN : the official journal of the Hospice and Palliative Nurses Association, 20*(2), 137–145. https://doi.org/10.1097/NJH.0000000000000417

Abdel Razeq, N. M., & Al-Gamal, E. (2021). Informing mothers of neonatal death and the need for family-centered bereavement care: A phenomenological qualitative study. *Journal for specialists in pediatric nursing : JSPN, 26*(2), e12328. https://doi.org/10.1111/jspn.12328

Armentrout, D.C. (2007). Holding a Place: Parents' Lives Following Removal of Infant Life Support. *Newborn and Infant Nursing Reviews, 7.*

Azeez, S., Obst, K. L., Due, C., Oxlad, M., & Middleton, P. (2022). Overwhelming and unjust: A qualitative study of fathers' experiences of grief following neonatal death. *Death studies, 46*(6), 1443–1454. https://doi.org/10.1080/07481187.2022.2030431

Barr, P. (2011). Posttraumatic growth in parents of infants hospitalized in a neonatal intensive care unit. *Journal of Loss and Trauma, 16*(2), 117–134. https://doi.org/10.1080/15325024.2010.519265

Bennett, S. M., Litz, B. T., Lee, B. S., & Maguen, S. (2005). The Scope and Impact of Perinatal Loss: Current Status and Future Directions. *Professional Psychology: Research and Practice, 36*(2), 180–187. https://doi.org/10.1037/0735-7028.36.2.180

Brooten, D., Youngblut, J. M., Caicedo, C., & Dankanich, J. (2019). Parents: Wish I had done, wish I had not done, and coping after child NICU/PICU death. *Journal of the American Association of Nurse Practitioners, 31*(3), 175–183. https://doi.org/10.1097/JXX.0000000000000110

Burden, C., Bradley, S., Storey, C., Ellis, A., Heazell, A. E., Downe, S., Cacciatore, J., & Siassakos, D. (2016). From grief, guilt pain and stigma to hope and pride - a systematic review and meta-analysis of mixed-method research of the psychosocial impact of stillbirth. *BMC pregnancy and childbirth, 16*, 9. https://doi.org/10.1186/s12884-016-0800-8

Christiansen, D. M., Elklit, A., & Olff, M. (2013). Parents bereaved by infant death: PTSD symptoms up to 18 years after the loss. *General hospital psychiatry, 35*(6), 605–611. https://doi.org/10.1016/j.genhosppsych.2013.06.006

Clark, O. E., Fortney, C. A., Dunnells, Z. D. O., Winning, A. M., Gerhardt, C. A., & Baughcum, A. E. (2021). Parents' own words: Adjustment and coping following infant death in the NICU. *Clinical Practice in Pediatric Psychology, 9*(3), 261–271. https://doi.org/10.1037/cpp0000418

Creswell, J.W. and Plano Clark, V.L. (2011) Designing and Conducting Mixed Methods Research. 2nd Edition, Sage Publications, Los Angeles

Currie, E. R., Christian, B. J., Hinds, P. S., Perna, S. J., Robinson, C., Day, S., Bakitas, M., & Meneses, K. (2019). Life after loss: Parent bereavement and coping experiences after infant death in the neonatal intensive care unit. *Death studies, 43*(5), 333–342. https://doi.org/10.1080/07481187.2018.147428

Haddaway, N. R., Collins, A. M., Coughlin, D., & Kirk, S. (2015). The Role of Google Scholar in Evidence Reviews and Its Applicability to Grey Literature Searching. *PloS one, 10*(9), e0138237. https://doi.org/10.1371/journal.pone.0138237

Hartling, L., Featherstone, R., Nuspl, M., Shave, K., Dryden, D. M., & Vandermeer, B. (2017). Grey literature in systematic reviews: a cross-sectional study of the contribution of non-English reports, unpublished studies and dissertations to the results of meta-analyses in child-relevant reviews. *BMC medical research methodology, 17*(1), 64. https://doi.org/10.1186/s12874-017-0347-z

Kenner, C., & Lott, J. W. (Eds.). (2014). Comprehensive neonatal nursing care (Fifth edition.). Springer Publishing Company.

Kimble D. L. (1991). Neonatal death: a descriptive study of fathers' experiences. *Neonatal network : NN, 9*(8), 45–49.

Laakso, H., & Paunonen-Ilmonen, M. (2001). Mothers' grief following the death of a child. *Journal of advanced nursing, 36*(1), 69–77. https://doi.org/10.1046/j.1365-2648.2001.01944.x

Lakhani, J., Mack, C., Kunyk, D., & van Manen, M. (2023). Exploring and Supporting Parents' Stories of Loss in the NICU: A Narrative Study. *Qualitative health research, 33(*14), 1279–1290. https://doi.org/10.1177/10497323231201023

Lannen PK, Wolfe J, Prigerson HG, Onelov E, Kreicbergs UC. Unresolved grief in a national sample of bereaved parents: Impaired mental and physical health 4 to 9 years later. *Journal of Clinical Oncology. 2008;26*(36):5870–5876. doi: 10.1200/JCO.2007.14.6738

Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc. 2015;13*(3):179–187

Manju, V., Paul, V. K., Manju, M., & Srinivas, M. (2012). Loss and grief response and perceived needs of parents with the experience of having their newborn at neonatal care units. *International Journal of Nursing Education, 4*(2).

Nii Laryeafio, M., & Ogbewe, O.C. (2023). Ethical consideration dilemma: systematic review of ethics in qualitative data collection through interviews. *Journal of Ethics in Entrepreneurship and Technology.*

Orb, A., Eisenhauer, L., & Wynaden, D. (2001). Ethics in qualitative research. *Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing, 33*(1), 93–96. https://doi.org/10.1111/j.1547-5069.2001.00093.x

Paez A. (2017). Gray literature: An important resource in systematic reviews. *Journal of evidence-based medicine, 10(*3), 233–240. https://doi.org/10.1111/jebm.12266

Petticrew, M. and Roberts, H. (2008) Systematic Reviews in the Social Sciences: A Practical Guide. John Wiley & Sons, Hoboken.

Reuvers, E. (2018). Parental Loss and Grief in the Neonatal Intensive Care Unit: A Systematic Review of Qualitative Evidence.

Rowe, Wendy E. “Positionality.” The Sage Encyclopedia of Action Research, edited by Coghlan, David and Mary Brydon-Miller, Sage, 2014.

Stoll, C. R. T., Izadi, S., Fowler, S., Green, P., Suls, J., & Colditz, G. A. (2019). The value of a second reviewer for study selection in systematic reviews. *Research synthesis methods, 10*(4), 539–545. https://doi.org/10.1002/jrsm.1369

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology, 8*, 45. https://doi.org/10.1186/1471-2288-8-45

World Health Organisation (2023) Preterm birth [online]. Available from: https://www.who.int/newsroom/fact-sheets/detail/preterm-birth (Accessed 6 September 2024).

Wray, A., Pickwell-Smith, B., Greenley, S., Pask, S., Bamidele, O., Wright, B., Murtagh, F., & Boland, J. W. (2022). Parental death: a systematic review of support experiences and needs of children and parent survivors. BMJ supportive & palliative care, bmjspcare-2022-003793. Advance online publication. https://doi.org/10.1136/spcare-2022-003793

Youngblut, J. M., Brooten, D., Glaze, J., Promise, T., & Yoo, C. (2017). Parent Grief 1-13 Months After Death in Neonatal and Pediatric Intensive Care Units. *Journal of loss & trauma, 22*(1), 77–96. https://doi.org/10.1080/15325024.2016.1187049

Appendices

Appendix A- Quality Appraisal table of studies strengths and limitations.

Author (S) & Year	Strengths	Limitations
Aagaard, Storm & Klitgaard, 2016	Continuous discussion between research team to avoid researcher bias.	Focuses on one couple of one baby only- hard to generalise to wider population of NICU babies.
Abdel Razeq & Al-Gamal, 2018	Cross-examination of categories and themes to reduce researcher bias.	Participants from one geographical area- lack of generalisability across areas .
Abdel Razeq & Al-Gamal, 2021	Regular team meetings held to discuss data gathered and limitations to maintain trustworthiness of study.	Data gathered from one geographical area only- lack generalisability across areas. Unconscious researcher bias may have impacted as researchers are from the same cultural background of participants.
Armentrout, 2007	Large quotes used in findings- clearly depicts participants individual stories.	Lack of ethnically diverse participants- hard to generalise results across cultures.
Azeez, Obst, Due, Oxlad & Middleton, 2022	Participants able to provide feedback on their transcript- increase validity of findings.	Lack of diversity- all fathers were with mother and were employed. All participants from one geographical area- lack of generalisability.

	Clear self reflexivity and impact on research- reduce bias.	
Clark, Fortney, Dunnells, Winning, Gerhardt & Baughcum, 2021	Themes analysed until consensus and saturation was reached. Open-ended questions used to give spontaneous data.	One geographical area- lack of generalisability. Opt in recruitment strategy. Lack of diversity in sample. Retrospective report- recall bias.
Currie, Christina, Hinds, Perna, Robinson, Day, Bakitas & Meneses, 2019	Debriefing authors and reflecting on position to enhance trustworthiness. Findings were reviewed with participants to ensure accurate representations of their views- increase validity.	Lack of ethnically diverse sample. Not representative across cultures Sample from one geographical area- lack of generalisability.
Geetanjli, Manju, Mehta Manju & Srinivas, 2012	Credibility ensures by using person triangulation by multiple data sources.	Single centre study- lack of generalisability. Member checking could not be done.
Kimble, 1991	Some participants reviewed findings to ensure accurate representation of participant views- increasing validity.	All fathers participated for altruistic reasons- sample may be biased towards those who are ready to discuss experiences in this way.

		All participants had attended a bereavement group- may have processed grief better. Lack of quotes from interviews used- difficult to understand the experiences of parents. No clear analysis stated.
Lakhani, Mack, Kunyk & van Manen, 2023	None of the research team had clinical contact with families therefore families could speak openly without worry about the impact on their care. Homogenous sample- achieve greater depth as narrative analysis aims to do. Used one open question to start conversation only- individuals then allowed to discuss their stories freely. Multiple authors contributed to analysis- reduce researcher bias.	Small sample size from single geographical area and institution- limited generalisability. Homogenous sample- all had a partner for support- experiences may be different in those who are lone parents or no support.

Appendix B- JBI Critical Appraisal for Qualitative Research Checklist

JBI Critical Appraisal Checklist for Qualitative Research

Reviewer_________________________________Date_________________________

Author___________________________________Year________Record Number ______

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐

6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

Appendix C- JBI Critical Appraisal Checklist for each study included in the review

JBI Critical Appraisal Checklist	Aagard et al. 2016	Abdel Razeq & Al-Gamal, 2018	Abdel Razeq & Al-Gamal, 2021	Armentrout, 2007	Azeez et al. 2022	Clark et al. 2021	Currie at al. 2019	Geetanjli et al. 2012	Kimble, 1991	Lakhani et al. 2023
Is there congruity between the stated philosophical perspective and the research methodology?	U	Y	Y	Y	Y	U	Y	Y	Y	Y
Is there congruity between the research methodology and the research question or objectives?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is there congruity between the research methodology and the methods used to collect data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Is there congruity between the research methodology and the representation and analysis of the data?	Y	Y	Y	Y	Y	Y	Y	Y	U	Y
Is there congruity between the research methodology and the interpretation of the results?	U	Y	Y	Y	Y	Y	Y	Y	U	Y
Is there a statement locating the researcher culturally or theoretically?	N	U	Y	N	N	N	N	U	N	N
Is the influence of the researcher and the research, and vice versa addressed?	N	N	U	N	Y	N	N	N	N	U
Are participants and their voices adequately represented?	Y	Y	Y	Y	Y	Y	Y	U	U	Y
Is the research ethical according to current criteria or for recent studies, and is there evidence of ethical approval by an appropriate body?	Y	Y	Y	Y	Y	Y	Y	Y	N	Y

Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	Y	Y	Y	Y	U	Y
Totals:	6/ 10 Y 2/10 N 2/10 U	8/10 Y 1/10 N 1/10 U	9/10 Y 1/10 U	8/10 Y 2/10 N	9/10 Y 1/10 N	7/10 Y 2/10 N 1/10 U	8/10 Y 2/10 N	7/10 Y 1/10 N 2/10 U	3/10 Y 3/10 N 4/10 U	8/10 Y 1/10 N 1/10 U

Key: Y= Yes, N= No, U= Unclear

Paper Two: Empirical Research Paper

“It’s a place I will never forget”

Fathers’ Experiences of Neonatal Care: An Interpretative Phenomenological Analysis Study

Target journal: Qualitative Health Research

This paper has been prepared in accordance with author guidelines for the above stated journal (Appendix M). Final formatting edits will be made prior to submission to the journal.

Word count: 7989
(Excluding title page, references and appendices)

Abstract

Whilst a NICU journey is complex for all parents, fathers may make sense of their journey differently to mothers due to the differing role and pressures as a father. Research aiming to understand fathers' unique experiences of the NICU is limited. The current study aims to understand fathers' experiences and how they make sense of their journey in neonatal care.

Eight men who had an infant in neonatal care, were recruited via posters placed at one NHS NICU site, social media and via professional email groups of clinical psychologists working within neonatal care. Semi-structured interviews were used flexibly and analysed using Interpretative Phenomenological Analysis.

Three Group Experiential Themes (GETs) with a total of nine group level subthemes were identified: 'The emotional rollercoaster', 'The hidden not heard experience', and 'The people around you: help or hinder?'.

Findings depict that fathers have conflicting opinions about accessing formal support for their experiences and differing opinions about if and who they talk to about their experiences. Services need to tailor support interventions to ensure they meet the individual needs of fathers. Fathers face barriers and facilitators to accessing support such as socio-cultural norms and ideas of masculinity and duty which may impact on father's experiences.

Keywords: Neonatal, Father, Dads, NICU, Experiences

Introduction

Every year, over 100,000 babies are cared for in a NICU in the UK, following being born premature, before 37 weeks of pregnancy, or are unwell (NDAU, 2017). Having an infant on a Neonatal Intensive Care Unit (NICU) can be highly distressing and traumatic for both parents. The NICU is a unique environment filled with a range of stressors including grief, complex medical decision making, lack of parent-infant bond, separation, and being surrounded by harrowing sights and sounds (Hassan et al., 2023). As a result, parents experience a range of emotions whilst on the unit such as anxiety, depression and fear (Baia et al., 2016), with parents of infants who receive neonatal care showing greater levels of stress than those whose infants do not require neonatal care following birth (Shaw et al., 2009). However, much of this research that documents the experiences and challenges faced by parents on the NICU, includes mother and father perspectives together which ignores the potential different challenges between mothers and fathers and creates a ‘one-size-fits-all’ approach to support.

Fathers are often the first parent onto the NICU with their infant, with mothers possibly requiring medical treatment, or be seriously unwell, and not having capacity to make urgent medical decisions. This leads to fathers having to make complex medical decisions alone adding to their emotional turmoil. Fathers are torn between being with their infant and being with their partner, causing psychological turmoil (Merritt et al., 2021), combined with wider responsibilities such as caring for other children and employment (Feeley et al., 2013). This makes for a differing experience, facing different challenges, to that of mothers.

Fathers can feel excluded from caring for their infant, leading to feeling isolated and a perceived lack of control (Osborne et al., 2024). Involving fathers in the care of their infant not only improves the mental health of the father but also reduces symptoms of post-partum depression in mothers (Kim et al., 2020). These unique experiences of fathers must be understood in detail to provide individualised support that is effective for fathers on the NICU (Merritt et al., 2022), however there is a paucity of research examining fathers’ experiences of neonatal care.

Fathers have previously reported to feel excluded by maternity support services and do not feel they can access support (Darwin et al., 2017), with fathers feeling the aim of services is to ‘support mum’ only and not a service to support their journey (Govindaswamy et al., 2020), causing fathers to suffer in silence. Research has shown that fathers of preterm babies have significantly higher rates of persisting anxiety and lower quality of life scores compared to fathers of term babies (Peterson & Quinlivan, 2021). Depression has been found in parents of premature infants and term infants within the NICU, regardless of the length of stay or the severity of ill-health of the infant (Nillni et al., 2018). Thus, evidencing the drive to understand father specific experiences of the NICU to ensure fathers are being supported.

A report by the ‘Baby Loss and Maternity, All Parliamentary Groups’, highlighted the impact of staffing pressures on neonatal care, stating that staff felt burnt out, stretched and having to take on responsibilities outside the remit of their roles. Parents of infants reported that staff struggled to provide adequate care for infants. The report evidenced that parents had witnessed the impact of staff shortages, and this had affected their experience on the NICU (Baby Loss and Maternity All Party Parliamentary Groups, 2022). Current NHS challenges may lead to different experiences for fathers within England compared to fathers' experiences in other countries. No previous research has looked at fathers in England alone.

Previous research that has explored father experiences has excluded some fathers based on the gestation of the infant, including mainly premature infants in the research only (Barton et al., 2021), or by excluding infants with specific medical conditions. However, infants are admitted to the NICU for a wide range of reasons such as prematurity, ill health at full term, following a traumatic birth, having an infection and awaiting to have or recovering from complex surgery (Merritt et al., 2022). Therefore, each journey can be vastly different and unique, and no experiences should be excluded if research is going to accurately understand fathers' experiences of the NICU. The current study endeavours to incorporate a range of NICU journeys to build this gap in existing research.

It is important to understand the specific stories of fathers and their experiences as research has documented that father's mental health can be associated with negative outcomes for children, including emotional and behavioural problems, independent of maternal mental health (Ramchandani et al., 2005). Parents of infants who have had a NICU admission have also reported relationship difficulties years after their NICU stay, potentially due to the emotional strain experienced by parents (Bernardo et al., 2021). These adverse effects of a NICU admission on parents, illustrates the need to understand fathers' experiences in detail, potentially improving the support offered to fathers by services and inform service provision.

Research aims

Whilst there have been attempts to understand fathers' experiences of NICUs, these have been limited for the reasons outlined above and implications are therefore difficult to draw out for the NHS. There is a need to understand the commonalities across fathers' experiences as well as their personal stories. This research aims to understand fathers' experiences in the NICU, provide new insights into the similarities and differences amongst paternal experiences of NICU's in England and suggest clinical improvements in the support offered to fathers throughout their NICU journey in the NHS.

Research question: How do fathers experience their infants' stay on a NICU within England?

Method

Research design

This qualitative study uses Interpretative Phenomenological Analysis (IPA), adopting terminology and analysis methods by Smith et al. (2022). IPA adopts a double hermeneutic approach which involves the researcher reflecting on and attempting to interpret participants' reflections of their journey to develop a deeper and richer understanding of the phenomenon being studied (Smith et al., 2022). This is important for this research as it as a topic which is under-researched. A phenomenological approach enables the researcher to gain a true and detailed understanding of participants experiences (Alase, 2017).

IPA was chosen due to its epistemological and ontological position being best suited to answering the research question aims of understanding individual subjective experiences of the psychological experiences, encountered by fathers with an infant/s in a NICU. Compared to other qualitative approaches such as thematic analysis, IPA enables individual stories to be heard and compared within the research, highlighting convergence and divergence between fathers' experiences. Narrative analysis methodology was ruled out as it focuses on sense making of significant change(s) in one's personal narrative over a period of time, rather than focussing on individual interpretation of a specific phenomenon.

Participants

Participants were recruited using a purposive sampling method; this ensures reasonable homogeneity within the sample, to allow in-depth exploration (Smith et al., 2022). Eight eligible participants took part in this study sharing the similar characteristics of being a father of an infant who has experienced a NICU admission in England. IPA enables the researcher to understand the experience of each individual whilst still finding recurrent themes across the group, eight participants are deemed suitable to provide this rich data to answer the research aims (Smith et al., 2022). The recruitment poster (see Appendix A) was displayed on social media sites such as Instagram, Facebook and LinkedIn, charities providing support to NICU families both locally and nationally and individual professional and support accounts related to NICU displayed the poster. The poster advertisement was also displayed within an approved NHS Trust: University Hospitals of Derby and Burton NHS Foundation Trust. The advertisement was also shared via e-mail within a professional group of psychologists working within NICU's within England. Personal participant demographics were not gathered due to the potential that participants could be identified from their accounts and linked to the NHS service. Previous research has evidenced these ethical concerns when studying in-depth a small pool of individuals (Mozersky et al., 2020). The study focused on the births and stays within the NICU and how this may have affected paternal experiences and informed interpretation of meaning. Demographic data with relevant details for this study, are displayed in Table 1.

Table 1

Characteristics of participants NICU stays

Participants	Infant (s) gestation	Length of stay on NICU	Length of time since stay on NICU	Number of siblings at time of NICU stay	Amount of NICU stays for family	NICU Infant (s)
Aaron	30 weeks	4 weeks	1 year	0	1	Alive
Billy	30 weeks	8 weeks	4 years	0	1	Alive
Curtis	25 weeks	19 weeks	3 months	1	1	One twin passed; one twin alive
Darren	Full term	5 days	9 years	0	1	Alive
Edward	33 weeks	2 weeks	3 years	2	1	Alive
Freddie	Full term	8 weeks	5 years	0	1	Alive
Gavin	29 weeks	6 weeks	4 years & 1 year	1	2	Alive
Harry	25 weeks	15 weeks	1 year	1	1	Alive

Study inclusion and exclusion criteria

Individuals could take part in the study once their infant had been discharged from the unit for at least 4 weeks, except if they identified themselves as experiencing a mental health crisis or currently receiving support from a mental health service, as to avoid further distress. All infants of participants had a NICU admission within neonatal care in England. Individuals were aged at least 18 years of age and spoke fluent English. This was due to ethical and safeguarding concerns of recruiting young people and the researcher not receiving funding to use interpreters for the research.

Ethics

Ethical approval for this study was granted by the University of Staffordshire's Ethics Committee (see Appendix B). The study received REC approval with the committee deeming the study to not need HRA approval (see Appendix C). Participant confidentially and anonymity was upheld by using participant pseudonyms. All data from participants was stored securely on the researcher's, University account.

Participants were informed that they could take a break from or stop the interview at any time. There were no occasions that participants asked to pause or stop the interview. Participants were provided with a debrief form (see Appendix D) after the interview signposting them to relevant support services should they require emotional support following the interview.

Procedure

Full details of the procedure of this study can be found in Figure 1. Data was collected between May 2024 and November 2024 from eight participants. Altogether, 13 individuals expressed an interest in taking part and received the Participant Information Sheet (PIS) (see Appendix E) and Consent Form (see Appendix F). All individuals that showed interest in the study were recruited via social media posts. Eight individuals consented and were interviewed online using Microsoft Teams. Data collection ended in November 2024 and the decision was based on the ability to complete the project competently within the timeframe of the doctoral course.

Figure 1

Study Procedure.

Participants saw the poster advertisement and then emailed the researcher to express interest in the study. Participants were then sent the PIS and consent form by email.

↓

Participants who wanted to take part in the study then signed and returned the consent form to the researcher by email.

Once the researcher received the signed consent form from participants, the researcher emailed each participant to arrange a mutually convenient time to complete the interview. At completion of the interview, participants were provided with a debrief form.

An interview schedule was co-developed between the researcher, project supervisors and a father with NICU experience (see Appendix G). The questions were initially based upon gaps in the literature on parental and father-specific experiences of the NICU, combined with knowledge from the clinical field supervisor about important areas that needed to be understood. The proposed interview questions were then shared with the father, who reviewed their appropriateness and suggested that a question exploring support for fathers would be important, which was added to the interview schedule. Interview length ranged from 35 to 71 minutes.

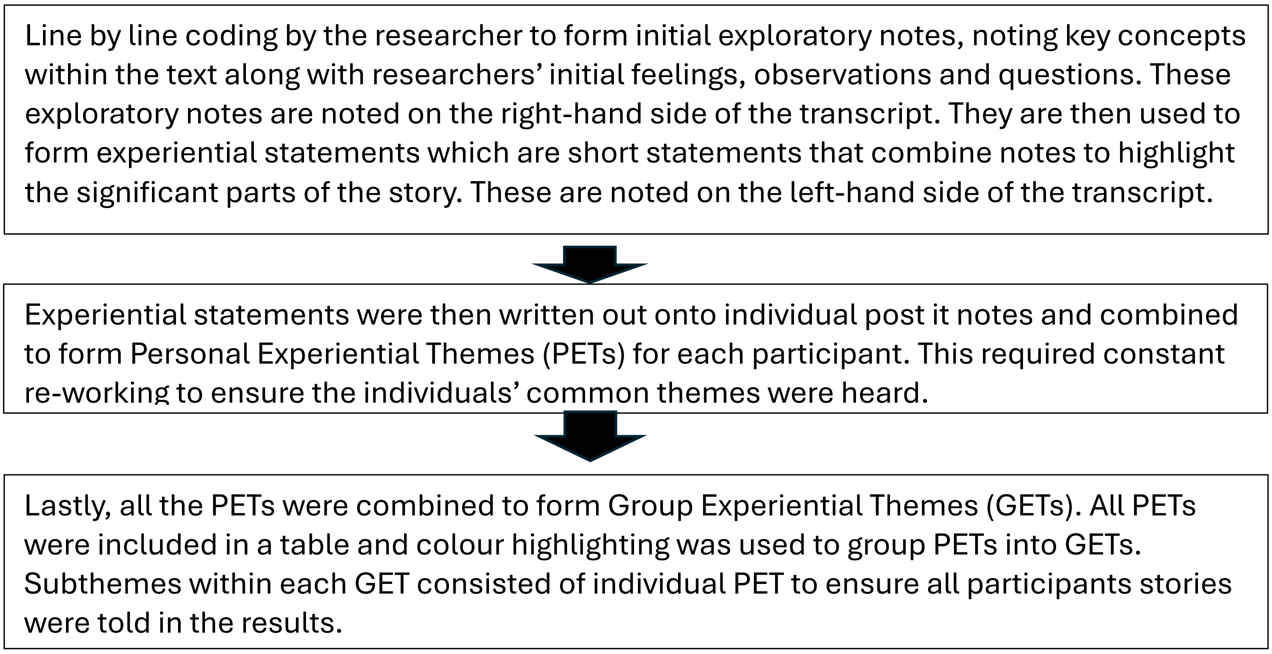
To allow engagement with individual participant's accounts and to hear their personal stories, the interview schedule was used flexibly, so individuals could tell their story how they chose, in whatever order. Some of the questions in the interview schedule were answered naturally in participants accounts without prompts by the researcher. In other interviews the schedule was used more closely to cover areas the researcher wanted to gain insight into.

Analysis

The interviews were recorded using Microsoft Teams. Each interview was transcribed by the researcher only. After transcription, each interview was read multiple times to familiarise with the content before beginning analysis. The IPA analysis process depicted by Smith et al. (2022) was followed by the researcher, details of the process can be found in Figure 2.

Figure 2

Analysis Process (Smith et al., 2022).



Line by line coding by the researcher to form initial exploratory notes, noting key concepts within the text along with researchers' initial feelings, observations and questions. These exploratory notes are noted on the right-hand side of the transcript. They are then used to form experiential statements which are short statements that combine notes to highlight the significant parts of the story. These are noted on the left-hand side of the transcript.

Experiential statements were then written out onto individual post it notes and combined to form Personal Experiential Themes (PETs) for each participant. This required constant re-working to ensure the individuals' common themes were heard.

Lastly, all the PETs were combined to form Group Experiential Themes (GETs). All PETs were included in a table and colour highlighting was used to group PETs into GETs. Subthemes within each GET consisted of individual PET to ensure all participants stories were told in the results.

Examples of the IPA analysis process including an annotated transcript, picture depicting the creation of PETs for one participant, table illustrating the creation of GETs and a master table of all GETs with example participant quotes for each theme can be found in the appendices (appendix H-K).

Reflexivity

An integral part to IPA, is the double hermeneutic process (Smith et al., 2022). It is imperative for the researcher to consider their own personal views upon the topic being researched and how this may influence their interpretation of the findings. The researcher had professional experience of neonatal care, having provided psychological support to families within a NICU and had preconceived ideas that they would hear stories consisting of trauma and difficult experiences only. The researcher worked with families that arguably were the most distressed in the NICU who had reached out for psychological support, leading the researcher to feel that the NICU is a highly emotive and distressing environment where people wanted psychological support. The psychological support offered varied, from helping people to make sense of the unusual environment to how they are feeling and finding ways to deal with difficult feelings and living with uncertainty. Often it was mothers only that received psychological support, most reported it to be beneficial and valued the space that psychologists gave them to explore their experiences.

The researcher was surprised when some of the interviews detailed the growth of fathers and how some of the fathers seemed to reflect that not all individuals do find the experience hugely traumatic and do not all require psychological support, changing the researchers view of the subject.

IPA aims to capture the subjective sense-making and experience of a personal phenomenon (Smith et al., 2022). This understanding of experience is consistent with the researcher’s relativist, constructivist epistemological stance, that the nature of experience is subjective and constructed through our unique perspectives of the world (Smith et al., 2022). Taking this position allowed the researcher to interpret each story as equally meaningful, prioritising the depth of personal experience over generalisability. IPA naturally involves a level of interpretation and reflection by the researcher. By the researcher taking a relativist position, this acknowledges that biases are inherent from the researcher and cannot be completely removed as interpretation is a subjective process. The researcher kept a reflective dairy following each interview and during the analysis process (appendix L), using ‘bracketing’ to highlight any potential views that may impact on the researchers’ interpretation to ensure the analysis was trustworthy (Gyollai, 2020).

Results

Results overview

Three Group Experiential Themes (GETs) with subthemes were developed (Table 2).

Table 2

Group Experiential Themes (GETs) and Subthemes

Group Experiential Theme	Subtheme	Participants contributing to Theme
The emotional rollercoaster	1.1 A thunderstorm of emotions	All participants
	1.2 The NICU experience lives on	All participants
	1.3 Grief is multi-faceted: from loss to growth	All participants
The hidden not heard experience	2.1 My duty as a man	All participants
	2.2 The strain of competing roles	All participants
	2.3 The unique experience of a NICU dad	All participants
The people around you: help or hinder?	3.1 Staff make a difference	All participants
	3.2 An extended family	All participants
	3.3 To talk or not to talk?	All participants

The emotional rollercoaster

This theme relates to fathers attempts to make sense of the extensive array of and sudden changes of emotions experienced throughout the NICU journey, from the darkest lows to the highest highs, this is a unique journey of fluctuating emotions.

1.1 A thunderstorm of emotions

Participants described the chaotic nature of the NICU, leaving them feeling bewildered on the unit: *“You're just whipped up in this, this, this I don't know, this like* *thunderstorm of. Just things that are totally out of control."* (Curtis), the use of the words 'whipped up in this…thunderstorm' depicted a feeling like they had little control over these terrible and scary, tumultuous conditions, that was happening around them.

"What the hell is going? What the hell happens now what? What, what sort of sort of happened? So, was always a bit of confusion?" (Gavin)

Some participants were unable to understand what was going on around them, being *"in their kind of isolated little world and not really knowing what is going on"* (Darren), leaving *"little time to compartmentalise it all"* (Curtis) and understand how they are feeling.

Considering the uncertainty on the unit, Billy and Harry reflected on this notion when talking about how quickly situations can change on the unit.

"You feel like you have to rush back, just in case they aren't alive when you when you come back." (Billy).

"Just such a rollercoaster. Some days you could go in and you'd be dead happy and then the next minute, something had happened" (Harry)

The ever-changing emotions seem to make it difficult to process each moment on the NICU. Notably, not all participants experienced the traumatic nature of the NICU. With one participant, seemingly highlighting that *"sometimes we can over traumatise things in a way"* (Edward). Overall, this sub-theme highlighted the variety in how participants experience and make sense of their raw emotions through an uncertain time but also the different trauma responses such as denial and confusion.

1.2 The NICU experience lives on

Many participants reflected on how the psychological impact of their journey was not felt until a period after discharge: *“I think the psychological toll, the emotional, the emotional exhaustion, is not really felt until afterwards.”* (Billy). With some only acknowledging during the interview, a time when they were directly asked about the experience, the impact of their journey upon themselves: *“Even now it still gets me, you know, like sitting, talking about it like this. You can feel it proper getting to you. It definitely chokes me up sometimes.”* (Harry), showing fathers do not realise the impact the journey has on them. With some hypothesising that their brain had been *“very good at forgetting traumatic events”* (Curtis), leading to the delay in processing of the emotional impact. There was a sense of shock and surprise from fathers about how unaware they were of how much they had buried their emotional experiences; this coupled with a prolonged period of crying when fathers attempted to access their memories of the event.

Others felt they did not have time to process their emotions during the event, with the emotional impact then hitting at a later stage: *“hits you probably later really. I think at the time you don't process everything. You just do what's best for people.”* (Edward). Edward depicting here that he felt he needed to avoid his emotions so he could focus on looking after people, suggesting a father does not feel he is able to show emotions and equally be there for others.

Fathers continue to experience feelings of worry and concern after the end of their NICU stay about *“how vulnerable their infant is”* (Aaron) and their partner:

> *“I have to go and check on him constantly. I lie there listening to him breathing.”* (Harry)

“Convinced they were going to kill my wife by accident, or she was going to die and I think… I was just so overwhelmed with anxiety that it was going to happen again” (Darren)

Fathers also do not forget their NICU stay with the memories living on within them: *“And then just being in that environment again was really bad. I don't think I’ll ever get over that”* (Darren).

In these examples, the distinguishing feature is that the ‘NICU experience’ does not simply end once the family is discharged from the unit, fathers continue to live in fear of their infant or partner dying, seemingly extending the NICU impact on their lives, showing the NICU experience lives on.

1.3 Grief is multi-faceted: from loss to growth

Participants spoke about the unseen and forgotten losses of a stay on the NICU, Aaron spoke about *“the little Christmas photo shoots that we couldn’t have”* (Aaron), to *“we’ll be walking out with the baby carrier, and she’ll take a picture… but ours was quite different”* (Aaron). These forgotten losses, depict how fathers are grieving many different opportunities they were expecting to have with their infant, showing the complex nature of how grief within the NICU can present.

“Think one thing I've skimmed over is the impact of coming home without them. I think that was one of the worst experiences I've ever had… we got home, and they (family) decorated the house, and it was a really big reminder that they weren't here.” (Billy)

Conversely, some participants felt they had experienced growth from their NICU experience, Freddie spoke about developing his strength in being a parent having gone through a challenging time early on with his infant: *“I think it's made us better parents”* (Freddie). Furthermore, Gavin spoke about the benefits on the NICU experience on his relationship: *“it is massive (the journey) and it has helped for me and my wife. You know, we've shown we can work as a proper team which you need to as parents. So that's made us sort of more, stronger as a couple as well I think.”* (Gavin), along with a *“sense of achievement”* (Freddie) for many.

The NICU experience includes complex losses however some reflect that their journey changes them for the better. Whilst growth does not always follow loss, growth and trauma can coexist. This does not mean fathers forget about their experiences, but some discover meaning as they heal.

“It's not one I particularly perhaps would have wished to go on but having now gone through it and come out the other side, it's a place I will never forget for the good” (Harry).

The hidden not heard experience

Being a dad on a NICU is an extraordinary experience with varying roles and responsibilities. This theme highlights the unparalleled role of a NICU dad and the conflict and strain between their multiple roles as a dad, partner and male.

2.1 My duty as a man

Participants vocalised they avoided their emotions throughout the journey, focusing instead on the *“man’s role”* (Aaron) of *“holding things together…it’s my job here”* (Aaron). It appeared to be important for fathers to appear strong and not visibly display emotions. Fathers feel a responsibility to take on their partners emotions, trying to keep the situation as positive as possible, a way of supporting their partner through an otherwise quite helpless time for fathers where they may feel they cannot help in many other ways.

"I didn't get upset because I think my roles are, like, subconsciously was to reassure my wife and to make her feel like everything was going to be OK" (Billy)

"I feel I felt quite emotionally, surplus to requirements. I needed to maybe be there for her, but equally I could do so much less" (Curtis).

Here fathers are shielding themselves from the emotional impact, so they do not add to their partners perceived distress, whilst equally trying to be there for their partner but feeling that even being there emotionally for their partner is not enough, suggesting fathers feel redundant in their role as a partner and conflicted and distressed about how to support their partner.

Freddie spoke about the notion that fathers feel they do not have time to stop and process what is happening to them, suggesting the idea of 'duty' for fathers was to simply carry on and not take time to process how they are feeling: *"I just kind of took it in my stride and kind of had to. I think that's the key thing really. Kinda not really got any other choice."* (Freddie). Thus, leading some fathers to feel: *"it didn't really affect me too much, I'd like to think I'm quite a positive person"* (Aaron). By fathers reflecting on the 'stereotypical' role of a man, to keep going without thinking, it can be perceived that fathers do not acknowledge the emotional impact on themselves or live in denial of their experiences, with displays of emotions being counterproductive.

Overall, there is a sense of the duty that men feel to stay strong and positive can hinder their ability to recognise their emotions and process their responses.

2.2 The strain of competing roles

Fathers depicted that their stress stretches far wider than just the NICU, many spoke about the overwhelming challenges of the competing roles of a father, *“But by the time I've gone to work. Go and see him, do the dogs, blah, blah, blah. Then you'd be physically tired. You know what I mean? So, it was like you was getting drained from both mental and physical.”* (Aaron).

“You just frantically trying to live your life and look after your wife and kid, and you know and probably sort the house out as well.” (Gavin).

Suggesting that fathers have little to no time to compartmentalise their experiences, with being pulled physically and emotionally in multiple directions. This may add to fathers’ inability to recognise the emotional impact of the NICU whilst they are managing all their ‘expected’ responsibilities.

Although some reflected that the only thing that mattered during this time *“was your child being alive, your wife being alive and you being alive, and then nothing else really mattered.”* (Darren), seemingly depicting some fathers chose to block out wider pressures and their sole whole life becomes the NICU, and they don’t worry about wider roles.

Other participants spoke about their focus on the emotional impact, such as the worry about their partner following a traumatic birth: *“I was worried about my wife and that's probably the overarching feeling I had at the time. I was worried that she was going to die. And that was my first concern.”* (Edward). Whilst balancing their feelings about where they should be, fathers are often conflicted and torn about whether they should be with their infant or partner, their role as a partner and new father competing: *“where you're supposed to be, you're supposed to be like with the baby. You're supposed to be with your wife. I think that's probably the most difficult thing.”* (Freddie). Thus, showing a unique element of a fathers’ journey of the conflicting worry, surrounding multiple loved ones.

Fathers manage their multiple competing roles in different ways whilst on the NICU with some feeling a sense of their ‘role’ is to carry on managing responsibilities outside of the NICU with others seeing their ‘role’ as being present on the NICU only. From father to father, differences occur in what they see as ‘their role’ and their priorities. The role of a ‘father on the NICU’ is clearly not a one-dimensional experience.

2.3 The unique experience of a NICU dad

Being a ‘dad’ on a NICU is far from the traditional sense, participants shared their frustration about how little opportunity they had to be a ‘dad’ and do the things parents automatically expect to be able to do with their infant: *“it was just quite a bizarre time to have to ask permission to more or less look after your own child.”* (Billy). With a delayed sense of becoming a father: *“I suppose I hadn't really had a chance to kind of experience being a father or dad at that point”* (Darren). This may relate to the sense of another ‘duty’, of ‘being a father’, being unfulfilled and the emotional turmoil this causes for fathers.

Curtis did not identify as being a dad initially: *“not at any point would I have identified that I had the little ones, I was in their company in a room where I was not really able to get anywhere near them. You can't touch them. You can't parent them.”* (Curtis). However, when one of his infants sadly passed, he reflected in comparison, this was a time when he felt he could be a more traditional dad: *“Just have some...real time with her, where she was now just a little baby… But she didn't have any lines or tubes… And we could just hold her and do the things that you always want to do as a parent. And that felt really nice”* (Curtis). Suggesting the medical interventions provide a barrier between infant and father bonding leading to a sense of fathers feeling conflicted about if they are a father or not. Fathers want to feel physically connected to their infant to be able to develop their identity as a father.

In contrast, some participants reflected when looking back on their journey, that the experience had developed the bond between their infant and themselves rather than hindered it. The experience gave some time for just them and their infant to be alone which gave space for a stronger connection to develop.

"He kind of has like a little bit more connection with me and is that because, you know, in the first few days of his life, he saw more of me than he did his mum." (Edward).

"Certainly, the connection with him was like instant and it was powerful" (Harry).

Again, highlighting that the more time fathers can be physically present with the infant, the more connected they feel to their infant.

This theme depicted the complex nature of the role of 'being a father' on the NICU and the search for fathers to feel part of their infant's care. It appeared that fathers seek a physical connection to their infants to fulfil the emotional bond that drives their belief in their role as a father.

The people around you: help or hinder?

When considering the support participants want throughout their journey, individuals reflected on the impact various people had had on their experience, be this a help or a hindrance.

3.1 Staff make a difference

The bond between participants and staff working on the NICU affected their psychological experiences considerably. Some spoke about the positive nature of staff helped to give them a psychological boost: *“they make they made you feel like these little victories were really huge steps”* (Billy). By staff focusing on the seemingly small developments this helps parents to rationalise their journey, appearing to need this ‘boost’ to get through a difficult time. It's important to fathers to feel they and their family are being treated as individuals, not a number within a system.

“The amount of overwhelming love you receive from all the staff and the support and everything else, just sort of it really made you feel cared for and it that offset all the bad bits completely” (Harry)

Whilst others reflected on how the serious lack of communication from staff exacerbated their panic during an already turbulent time, leading to one father fearing their infant had died.

“One day we got there, and we walked into where he was the night before and his incubator was empty. So, I instantly like what's going on here. Has he died? Which first thing that's popped in your head, but all that happened is they moved him and not told us.” (Aaron).

Thus, clearly depicting a sense of the need for clear communication from staff for individuals to be able to process their journey and what is happening around them, *“I think sometimes it's taking the time to explain to us what's going on.”* (Edward).

It appeared important for fathers that staff treat them as individuals and acknowledge their wellbeing and experiences on the NICU.

3.2 An extended family

For many, their journey was supported by a sense of connectedness with other families on the NICU, as it helped fathers to feel *“you’re not alone”* (Curtis). Helping parents to *“feel more at ease, cause, they're sharing the same experience.*

Maybe not directly, but they're sharing the same kind of experience as you" (Aaron). This bond with other families seemingly supported fathers through their own journey, helping them to feel that there are others 'that get it', it appeared important for fathers to not feel alone in their experiences.

"I think that was one of the big things that really helped us through it all was that feeling of family." (Harry).

Whilst Edward who had other children alongside his infant, spoke about people assuming *'it's the only infant you've got'* (Edward), suggesting a feeling of disconnect between himself and other families as he had different responsibilities. Further supporting this notion of fathers wanting others to understand their experiences.

In comparison, Gavin reflected on the negative impact having families around had on his journey, depicting that fathers can project other families journeys onto their own, leading to increased unnecessary distress for some.

*"If you see something happen or you hear something happen, you know you hear bad news. You then start projecting that onto your own situation. You think? Well, ****, if that happens to this person, can it happen to us?"* (Gavin)

"it's just not what's happening to your kid it's what's happening to everybody else around as well that I think plays a big factor" (Freddie)

3.3 To talk or not to talk?

This subtheme illustrates individuals' experiences of sharing their journey with others. Whilst it can sometimes be assumed that *"talking about it helps a lot"* (Harry), many in fact spoke about their conflicting feelings to engage in professional support, highlighting individuals desire to have choice about whether to engage in support.

“And I think it's good not to have something forced down your throat really, because at the time you, you're dealing with a lot and you're probably not in the best place, but it's nice to have the information that you know if you needed something later.” (Edward)

“That is a double-edged sword because one I think you have a need for it, potentially. I think there's always nice to have the opportunity but to turn it down rather than not be offered something” (Curtis)

Potentially this linking to a man’s view of staying strong and not talking about their feelings: *“For men to talk, it takes a lot of guts, I think sometimes. You know, it's not, it's not a natural move for them to talk”* (Edward). It may be hard for men to appear vulnerable so may also subconsciously avoid support, so they do not fail in their ‘duty’ to stay strong.

“Could I have taken advantage of it more? Yes, 100%. Did I choose not to for my own sense of protecting myself from feeling vulnerable, yes.” (Curtis)

Many reflected that it was the informal opportunities to talk which helped the most, where fathers did not feel pressured to talk about deep feelings but could have choice about who and what they spoke about.

“I messaged my mates a few times…Talk to you a little bit and as soon as you've got it off your chest, you feel better already anyway.” (Aaron)

Overall, there is a sense that not all fathers need or want professional support, some find it inaccessible and intimidating, including more informal support measures helps fathers to feel at ease when processing their emotional responses.

“Part of it is the inaccessibility of the thing and the part of it is who's available to talk to. I think the option to have like a panel of dads that have been through this” (Freddie).

Discussion

Summary of findings

The study aimed to understand how fathers in England make sense of their experiences throughout neonatal care. The researcher arrived at a set of themes following the in-depth interpretation of participants sense making of their lives. Using IPA, three GETS, with nine subthemes were identified. The embedded clinical implications recommend that changes are made in neonatal care to support fathers more adequately. Potential implications and areas for future research are discussed.

The emotional rollercoaster

The array of emotions that fathers experience during their NICU journey, feelings of panic, to confusion and to growth, depicted the uncertainty in their journey. The results support previous research highlighting the fear and anxiety in parents (Cinar et al., 2017) along with the unpredictable nature of the NICU causing trauma (Barton et al., 2021). However, the current study adds to the existing literature by finding that not all fathers' find the experience traumatic. The current study highlighted how the NICU experience lives on for fathers whether this is a delayed processing of the events or their experiences effecting further births or their life after the NICU. Literature has not previously documented the findings of the multi-faceted nature of grief and loss on the NICU, looking at the unique missed opportunities fathers grieve such as memory making. Persson et al (2024) briefly touched on some of the perceived gains such as the strengthening of parental relationships whilst this research adds to the understanding of potential growth following a NICU stay such as a sense of achievement and feeling proud to have survived the journey. Alongside this, growth and trauma can coexist with distress, they are not opposites (Zoellner & Maercker, 2006). It should be acknowledged in psychological therapy that growth, does not erase the trauma but equally trauma does not stop growth. Therefore, growth does not mean that someone is ‘over it’ and not needing support.

Findings highlighted that many fathers do not process or acknowledge their emotions at the time of the stay, arguing that support whilst on the NICU may not be effective for all fathers. There appears a need for follow-up support, be this professionally or informal to be offered, for fathers a period of time after the NICU when fathers may have processed their emotional reactions and their experiences then subsequently having an impact on their lives at a later point. If fathers are not processing their emotions whilst on the unit, there is also a need for high levels of validation and normalisation from staff, offering fathers a space to process their experiences. Healthcare professionals need to consider the forgotten loses when supporting fathers; to consider not only the loss of an infant but that the grief reaction may present in various ways such as the loss of being able to take their infant home and the loss of memory making with family and friends.

The hidden not heard experience

The unspoken experiences of fathers, includes, striving to upkeep their duty and responsibility as a man by looking after their family, work and livelihoods and the pressures this brings, whilst caring for their family on the NICU were reflected in the current results (Merritt et al., 2023), along with not displaying emotions to protect their partner and potentially themselves and the somewhat untraditional experience of being a father on the NICU. Participants spoke about feeling that they needed to keep ‘their head up’ and positive for their partner, this seen as their ‘duty’ to protect their partner (Stefana et al., 2022). Similarly, participants reported in another study, the need to suppress their emotions to not burden their partner (Salazar, 2022) and shielding themselves to not ‘break down’ which would not be seen as an acceptable response to the situation (Hassan et al., 2023). Some spoke of not fulfilling their role of a dad whilst others spoke about the increase bond the experience had brought between them and their infant. Previous research has also depicted that fathers feel a close bond with their infant, due to the amount of time spent with them (Clarkson & Hearn, 2021). Interestingly, research has shown that fathers value being involved in infant care, the results from this study also suggest that by a father being involved in their infants’ care, this facilitates the development of their identity as a father (Stefana et al., 2018).

The findings recommend that fathers should be included in the care of and informed about their infant as much as possible to help fathers to fulfil their desire to be a father and feel included on the unit.

The people around you: help or hinder?

This theme spoke of the connections fathers made with people around them on the NICU, with them being both supportive and unhelpful to their experience (Feeley et al., 2013). Participants spoke of the need for effective communication from staff to manage their own emotional responses with those who experienced good support from staff seemingly finding their journey easier to get through, with others commenting on the impact that poor communication from staff had on their experiences. Whilst some spoke of the sense of ‘family’ on the unit and the support they received through this connection with others being beneficial, some reflected that they did not always want to bond with other families and did not find it helpful to be surrounded by the difficult situations of other families. Lastly, this theme clearly depicted not all fathers want to or feel able to access professional support. Other research has highlighted this reservation from fathers due to not wanting to feel ‘exposed’ or ‘vulnerable’ by speaking to a psychologist (Hassan et al., 2023). Recent research by Hassan et al (2023) further spoke of fathers who sought informal support by sharing experiences with other fathers. Similarly, this study found that fathers feel more comfortable speaking to other fathers or at least male professionals who they feel understand their journey more. Or simply some fathers do not feel the need to reach out for support with one seemingly to highlight that the experience was not traumatic.

Overall, some of the notions described in the current study such as difficulties faced by fathers regarding their expected roles and duties on the NICU can be explained through the consideration of masculinity and socio-cultural norms depicting how men ‘should’ behave in society (Noergaard et al., 2016), where the expectation is to be often emotionally suppressive and strong (Hassan et al., 2023). This potentially causing a barrier for fathers to access support during a challenging and vulnerable experience. Previous research has documented how fathers perceive ‘psychology as a threat’, fearing ‘being exposed and made vulnerable’ by a psychologist will lead to a ‘diminished sense of manhood’, potentially conflicting with their perceived role as a strong male and wanting to protect self, with fathers preferring to speak to other fathers instead (Hassan et al., 2023).

Services should consider that these findings demonstrate the need for individualised support. It should not be assumed that fathers either need or want formal talking support, but some may benefit from informal speaking to other fathers. Assumptions should not be made about support and distress and how or whether support is needed. Research shows that peer support offers fathers an effective safe place to share their experiences in which they can relate to one another, leading to the father to feel included, not alone, and validated (Archibald, 2019). With fathers who share their grief and sense of crisis with other fathers, shown to be able to process their experiences more easily (Laegteskov et al., 2023).

Services should consider the accessibility of the support that is offered, offering support throughout the day and during the evening, and who is offering this support, considering the gender and role of those offering support. Creative, informal ways to offer support such as ‘drop ins’ and ‘coffee mornings’ with fellow fathers may be beneficial. More males in professional support roles, particularly psychologists, being present in NICUs, may also benefit fathers, with research evidencing the importance of male staff members offering support within NICUs (Laegteskov et al., 2023). The way the NHS is currently offering psychological support appears to be ineffective for some fathers however a difficulty remains around how services can offer informal ways of support to be more accessible within a professional service.

Strengths and Limitations

To our knowledge, this is the first piece of research exploring the experiences of fathers in England, however, considering the homogeneity of the study, it is important to acknowledge that the results of this study highlight the experiences of a small sample of fathers within NHS NICU’s in England. The research could be improved by collecting demographics of fathers, particularly ethnicity, this would have added to the research, an understanding of any cultural difference of experience, coping, stigma and support seeking which would have enabled the research to make further clinical recommendations of what support may be effective for different groups.

A strength of this study is that it described and compared a variety of neonatal stays, not excluding any experiences based on length of stays or gestation of infant which to the best of our knowledge, no previous research has done, enabling a range of experiences to be understood. The study compared experiences of fathers with multiple children to those with just their infant on NICU, this highlighted some difference in the father’s wider responsibilities and associated stresses but also their differing opinions when having the time to access support and how they related to other families whose whole life is the NICU. This research offers an insight into some of the positive experiences for fathers such as their bonding with other families and staff, to their close connections with their infants and how their journeys have made them better parents and have stronger relationships with their spouses.

Future Research

Future research could focus on comparing the experiences of fathers with differing characteristics of NICU stays and differing wider personal responsibilities, for example exploring the experiences of those with multiple children alongside having their infant on the NICU compared to families with only their one infant on the NICU, exploring the experiences of those with extended stays on the NICU compared to those with shorter stays and exploring the experiences of those with infants with complex health needs compared to those with relatively healthy infants. By capturing a greater understanding of different types of neonatal journeys, this may highlight different support needs.

The current study highlighted mixed opinions of who fathers want to share their experiences with and who they want to reach out to for emotional support, if at all. Further research should aim to understand more about what exact support fathers want and need during their journey.

Conclusion

This research aimed to provide insight into the experiences of fathers within NHS neonatal care in England. Fathers face a range of experiences within neonatal care from a ‘roller-coaster of emotions’, with not all appearing to label the experience as ‘traumatic’, to the hidden experiences of ‘being a dad’ on the NICU to negotiating support and relationships with others. Services should endeavour to consider the support a father needs on an individual basis, widening the accessibility and suitability of support for all fathers throughout their journey.

References

Alase, A. (2017). The interpretative phenomenological analysis (IPA): A guide to a good qualitative research approach. *International journal of education and literacy studies, 5*(2), 9-19. DOI:10.7575/aiac.ijels.v.5n.2p.9

Archibald, S. J. (2019). What about fathers? A review of a fathers' peer support group on a Neonatal Intensive Care Unit. *Journal of Neonatal Nursing*, 25(6), 272-276. https://doi.org/10.1016/j.jnn.2019.05.003

Baby Loss and Maternity All Parliamentary Groups. (2022). Safe Staffing: The impact of staffing shortages in maternity and neonatal care. *House of Commons Library*.

Baía, I., Amorim, M., Silva, S., Kelly-Irving, M., de Freitas, C., & Alves, E. (2016). Parenting very preterm infants and stress in Neonatal Intensive Care Units. *Early human development, 101*, 3–9. https://doi.org/10.1016/j.earlhumdev.2016.04.001

Barton, N., Hall, C., & Risko, J. (2021). The lived experience of a NICU father: A descriptive phenomenological study. *Journal of Neonatal Nursing, 27*(3), 206-210.

Bernardo et al, 2021. 'Parental Stress and Mental Health Symptoms in the NICU: Recognition and Interventions'. *Neoreviews (2021) 22* (8): e496–e505.

Cinar, N., Kuguoglu, S., Sahin, S., & Altinkaynak, S. (2017). The experience of fathers having premature infants in neonatal intensive care unit. *Open J Pediatr Neonatal Care, 2*(1), 1-12.

Clarkson, G., & Hearn, G. (2021). Former Neonatal Intensive Care Unit Fathers' Involvement 4 Years Later: A Qualitative Study. *Journal of pediatric nursing, 60,* 31–39. https://doi.org/10.1016/j.pedn.2021.02.004

Darwin, Z., Galdas, P., Hinchliff, S., Littlewood, E., McMillan, D., McGowan, L., Gilbody, S., & Born and Bred in Yorkshire (BaBY) team (2017). Fathers' views and experiences of their own mental health during pregnancy and the first postnatal year: a qualitative interview study of men participating in the UK Born and Bred in Yorkshire (BaBY) cohort. *BMC pregnancy and childbirth, 17*(1), 45. https://doi.org/10.1186/s12884-017-1229-4

Feeley, N., Waitzer, E., Sherrard, K., Boisvert, L., & Zelkowitz, P. (2013). Fathers' perceptions of the barriers and facilitators to their involvement with their newborn hospitalised in the neonatal intensive care unit. *Journal of clinical nursing, 22*(3-4), 521–530. https://doi.org/10.1111/j.1365-2702.2012.04231.x

Govindaswamy, P., Laing, S., Waters, D., Walker, K., Spence, K., & Badawi, N. (2020). Stressors of parents of infants undergoing neonatal surgery for major non-cardiac congenital anomalies in a surgical neonatal intensive care unit. *Journal of paediatrics and child health, 56*(4), 512–520. https://doi.org/10.1111/jpc.14673

Gyollai D. Getting into it in the wrong way: Interpretative phenomenological analysis and the hermeneutic circle. *Nurs Philos*. 2020; 21:e12294. https://doi.org/10.1111/nup.12294

Hassan, H., Williams, F., Cordwell, J., & Mann, J. (2023). Ethnic minority fathers' experiences of the Neonatal Care Unit: barriers to accessing psychological support. *Journal of reproductive and infant psychology*, 1–13. Advance online publication. https://doi.org/10.1080/02646838.2023.2287079

Kim, T. H. M., Delahunty-Pike, A., & Campbell-Yeo, M. (2020). Effect of Fathers' Presence and Involvement in Newborn Care in the NICU on Mothers' Symptoms of Postpartum Depression. *Journal of obstetric, gynecologic, and* *neonatal nursing : JOGNN*, *49*(5), 452–463. https://doi.org/10.1016/j.jogn.2020.05.007

Merritt L. (2021). An Integrative Review of Fathers' Needs in the Neonatal Intensive Care Unit. *The Journal of perinatal & neonatal nursing, 35*(1), 79–91. https://doi.org/10.1097/JPN.0000000000000541

Merritt, L., Maxwell, J., & Urbanosky, C. (2022). The Needs of NICU Fathers in Their Own Words: A Qualitative Descriptive Study. *Advances in neonatal care : official journal of the National Association of Neonatal Nurses, 22*(3), E94–E101. https://doi.org/10.1097/ANC.0000000000000934

Mozersky, J., Parsons, M., Walsh, H., Baldwin, K., McIntosh, T., & DuBois, J. M. (2020). Research participant views regarding qualitative data sharing. *Ethics & human research, 42*(2), 13-27. https://doi.org/10.1002/eahr.500044

NDAU. (2017). NDAU 2016 report. Retrieved from: https://www.imperial.ac.uk/media/imperial-college/medicine/dept-medicine/infectious-diseases/neonatology/NDAU-2016-Report-v1.1-(002).pdf

Nillni, Y. I., Mehralizade, A., Mayer, L., & Milanovic, S. (2018). Treatment of depression, anxiety, and trauma-related disorders during the perinatal period: A systematic review. *Clinical psychology review, 66*, 136–148. https://doi.org/10.1016/j.cpr.2018.06.004

Noergaard, B., Johannessen, H., Fenger-Gron, J., Kofoed, P. E., & Ammentorp, J. (2016). Participatory Action Research in the Field of Neonatal Intensive Care: Developing an Intervention to Meet the Fathers' Needs. A Case Study. *Journal of public health research, 5*(3), 744. https://doi.org/10.4081/jphr.2016.744

Osborne, A.D., Yasova Barbeau, D., Gladdis, T. et al. Understanding and addressing mental health challenges of families admitted to the neonatal intensive care unit. *J Perinatol* (2024). https://doi.org/10.1038/s41372-024-02187-9

Persson, C., Ericson, J., Eriksson, M., Salari, R., & Flacking, R. (2024). Quality of couple relationship and associated factors in parents of NICU-cared infants during the first year after birth. *Journal of perinatology : official journal of the California Perinatal Association, 44*(12), 1738–1745. https://doi.org/10.1038/s41372-024-02076-1

Petersen, I. B., & Quinlivan, J. A. (2021). Fatherhood too soon. Anxiety, depression and quality of life in fathers of preterm and term babies: a longitudinal study. *Journal of psychosomatic obstetrics and gynaecology, 42*(2), 162–167. https://doi.org/10.1080/0167482X.2020.1808620

Ramchandani, P., Stein, A., Evans, J., O'Connor, T. G., & ALSPAC study team (2005). Paternal depression in the postnatal period and child development: a prospective population study. *Lancet (London, England), 365*(9478), 2201–2205. https://doi.org/10.1016/S0140-6736(05)66778-5

Salazar, B. L. (2022). Supporting the Paternal Role and Transition Home From the NICU: A Mixed Method Study. *The Open Journal of Occupational Therapy, 10*(2), 1-19. https://doi.org/10.15453/2168-6408.1838

Shaw, R. J., Bernard, R. S., Deblois, T., Ikuta, L. M., Ginzburg, K., & Koopman, C. (2009). The relationship between acute stress disorder and posttraumatic stress disorder in the neonatal intensive care unit. *Psychosomatics, 50*(2), 131–137. https://doi.org/10.1176/appi.psy.50.2.131

Smith, J. A., Flower, P., & Larkin, M. (2022). *Interpretative phenomenological analysis: Theory, method and research* (2nd ed.). SAGE Publications Ltd.

Stefana, A., Biban, P., Padovani, E. M., & Lavelli, M. (2022). Fathers' experiences of supporting their partners during their preterm infant's stay in the neonatal intensive care unit: a multi-method study. *Journal of perinatology : official journal of the California Perinatal Association, 42*(6), 714–722. https://doi.org/10.1038/s41372-021-01195-3

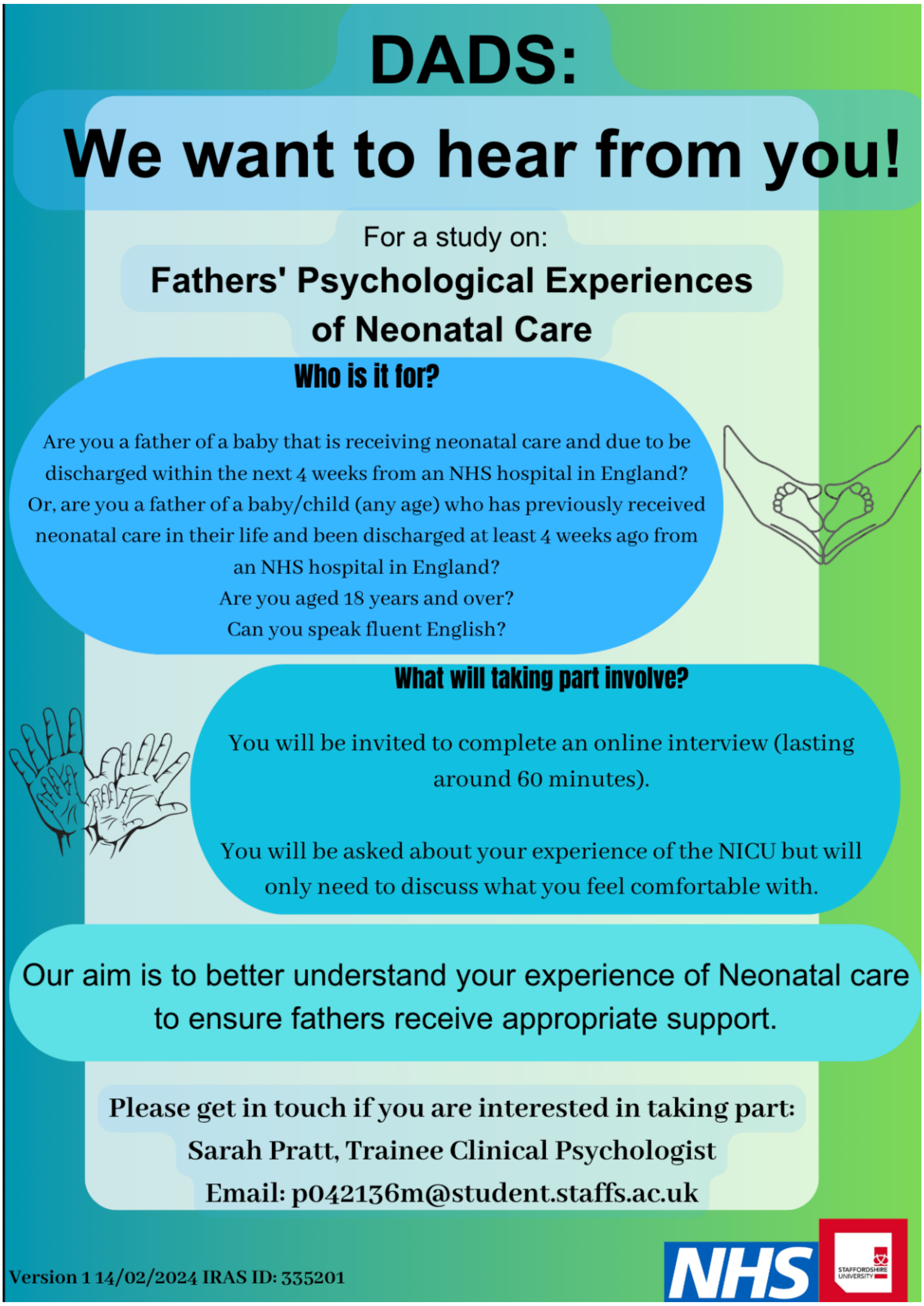
Stefana, A., Padovani, E. M., Biban, P., & Lavelli, M. (2018). Fathers' experiences with their preterm babies admitted to neonatal intensive care unit: A multi-method study. *Journal of advanced nursing, 74*(5), 1090–1098. https://doi.org/10.1111/jan.13527

Webber, C., Foran, P., & Walker, K. (2025). Fathers in the neonatal unit: A narrative review. *Journal of Neonatal Nursing*, 31(2), 101617. https://doi.org/10.1016/j.jnn.2025.101617

Zoellner, T., & Maercker, A. (2006). Posttraumatic Growth and Psychotherapy. In L. G. Calhoun & R. G. Tedeschi (Eds.), *Handbook of posttraumatic growth: Research & practice* (pp. 334–354). Lawrence Erlbaum Associates Publishers.

Appendices

Appendix A: Recruitment Poster



DADS:

We want to hear from you!

For a study on:

Fathers' Psychological Experiences of Neonatal Care

Who is it for?

Are you a father of a baby that is receiving neonatal care and due to be discharged within the next 4 weeks from an NHS hospital in England?
Or, are you a father of a baby/child (any age) who has previously received neonatal care in their life and been discharged at least 4 weeks ago from an NHS hospital in England?
Are you aged 18 years and over?
Can you speak fluent English?

What will taking part involve?

You will be invited to complete an online interview (lasting around 60 minutes).

You will be asked about your experience of the NICU but will only need to discuss what you feel comfortable with.

Our aim is to better understand your experience of Neonatal care to ensure fathers receive appropriate support.

Please get in touch if you are interested in taking part:
Sarah Pratt, Trainee Clinical Psychologist
Email: p042136m@student.staffs.ac.uk

Version 1 14/02/2024 IRAS ID: 335201

NHS
STAFFORDSHIRE UNIVERSITY

Appendix B: University ethical approval

Miss Sarah Pratt
Clinical Psychology
Staffordshire University

6th March 2024

Dear Sarah

Re: Fathers' Psychological Experiences of Neonatal Care: An Interpretative Phenomenological Analysis Study

Thank you for providing your NHS REC approval letter, which was dated 4th March 2024. It is noted that HRA approval was not required in this instance.

I am writing to confirm that the University IPR approval, issued on 8th February 2024, remains applicable. You can therefore commence your research, pending any relevant clearances from participating organisations.

Yours sincerely

Dr Edward Tolhurst
University IPR coordinator

STAFFORDSHIRE UNIVERSITY

INDEPENDENT PEER REVIEW APPROVAL FEEDBACK

Researcher Name	Sarah Pratt
Title of Study	Fathers' Psychological Experiences of Neonatal Care: An Interpretative Phenomenological Analysis Study
Status of approval:	**Approved**

Thank you for your submission to the Independent Peer Review (IPR) Panel. Your application is now approved.

Action now required:
You must now apply to the Integrated Research Applications System (IRAS) for approval to conduct your study. You must not commence the study without Health Research Authority (HRA) approval, and relevant site-specific approvals. Please note that the University Sponsor contact to be named on the form is Prof Nachi Chockalingam.

Please forward a copy of the letter you receive from the IRAS process to ethics@staffs.ac.uk as soon as possible after you have received approval.

Once you have received HRA approval, and participating Trusts/organisations have confirmed their capacity and capability to support your study, you can commence your research. You should be sure to do so in consultation with your supervisor.

You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved application.

When your study is complete, please send an end of study report to Dr Edward Tolhurst: e.tolhurst@staffs.ac.uk. A template can be found on the ethics Blackboard site.

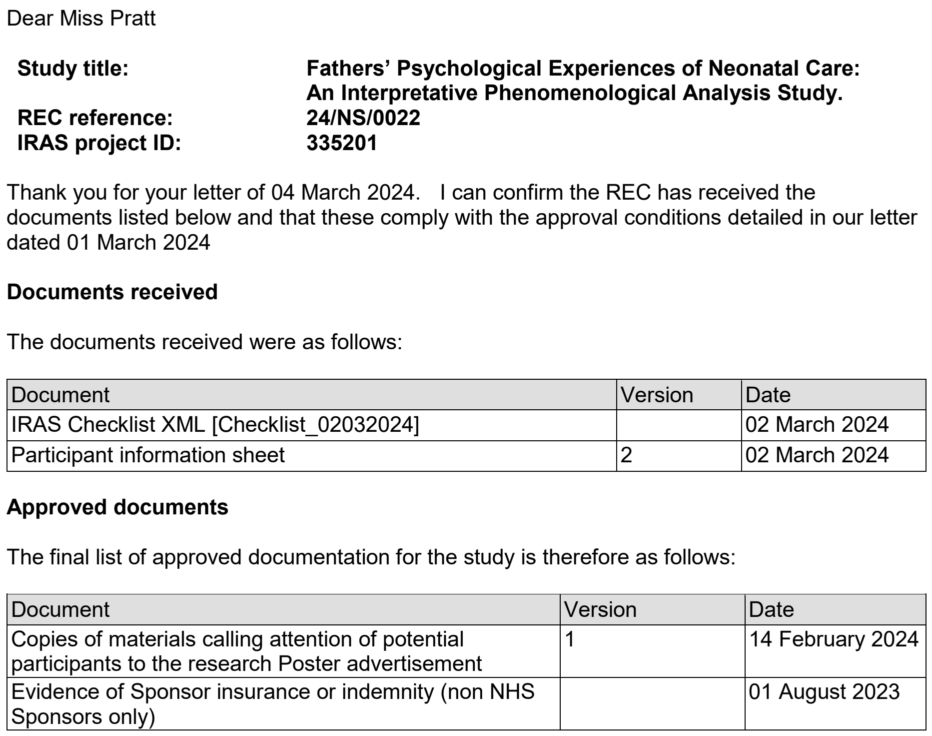
Comments for your consideration: In A37, it is sufficient for personal data to be stored securely on a University network drive.

E Tol

Signed: Dr Edward Tolhurst
University IPR coordinator

Date: 8th February 2024

Appendix C: REC Approval letter



Dear Miss Pratt

Study title: **Fathers' Psychological Experiences of Neonatal Care: An Interpretative Phenomenological Analysis Study.**
REC reference: **24/NS/0022**
IRAS project ID: **335201**

Thank you for your letter of 04 March 2024. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 01 March 2024

Documents received

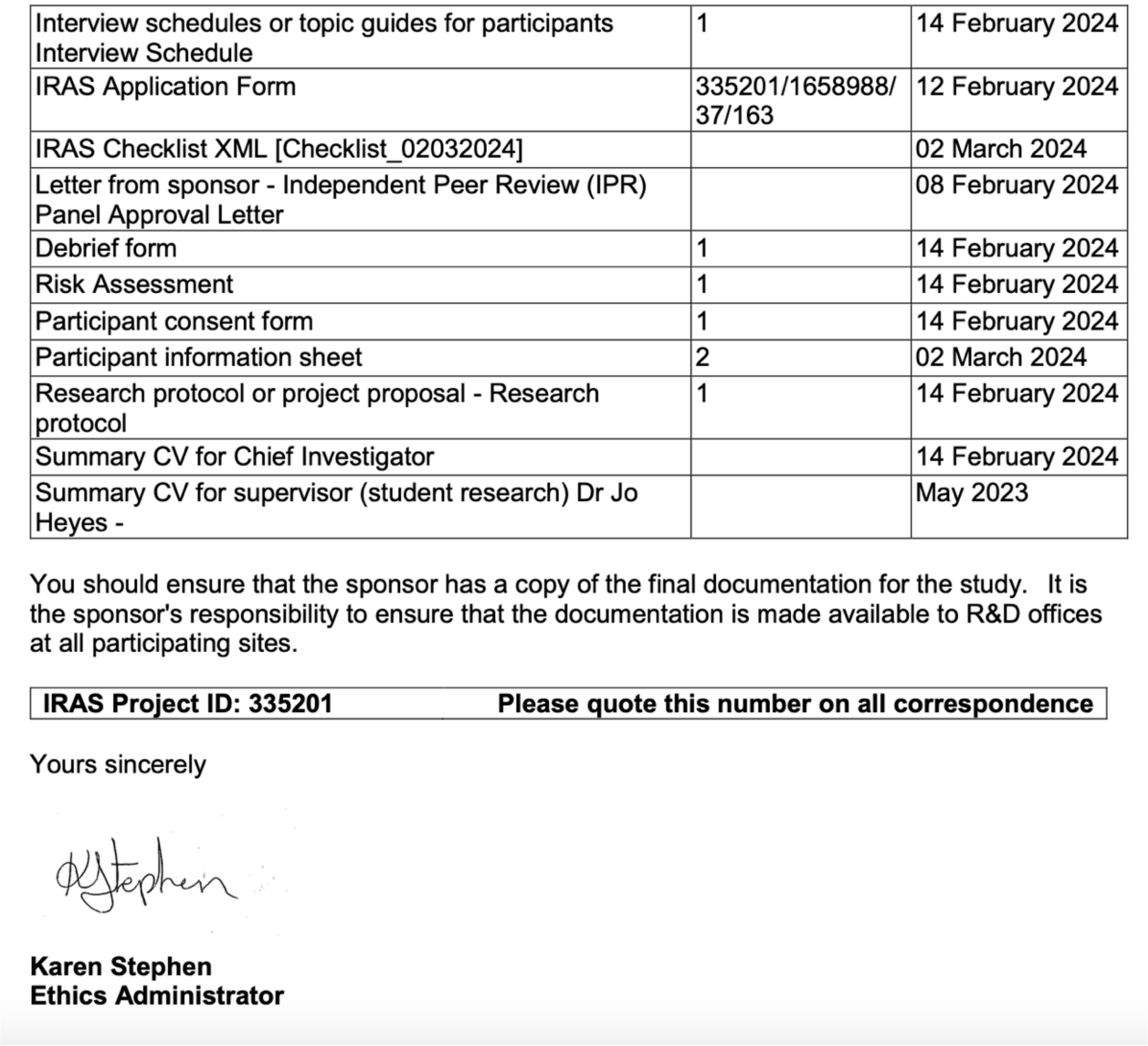
The documents received were as follows:

Document	Version	Date
IRAS Checklist XML [Checklist_02032024]		02 March 2024
Participant information sheet	2	02 March 2024

Approved documents

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

Document	Version	Date
Copies of materials calling attention of potential participants to the research Poster advertisement	1	14 February 2024
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		01 August 2023



Interview schedules or topic guides for participants Interview Schedule	1	14 February 2024
IRAS Application Form	335201/1658988/37/163	12 February 2024
IRAS Checklist XML [Checklist_02032024]		02 March 2024
Letter from sponsor - Independent Peer Review (IPR) Panel Approval Letter		08 February 2024
Debrief form	1	14 February 2024
Risk Assessment	1	14 February 2024
Participant consent form	1	14 February 2024
Participant information sheet	2	02 March 2024
Research protocol or project proposal - Research protocol	1	14 February 2024
Summary CV for Chief Investigator		14 February 2024
Summary CV for supervisor (student research) Dr Jo Heyes -		May 2023

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.

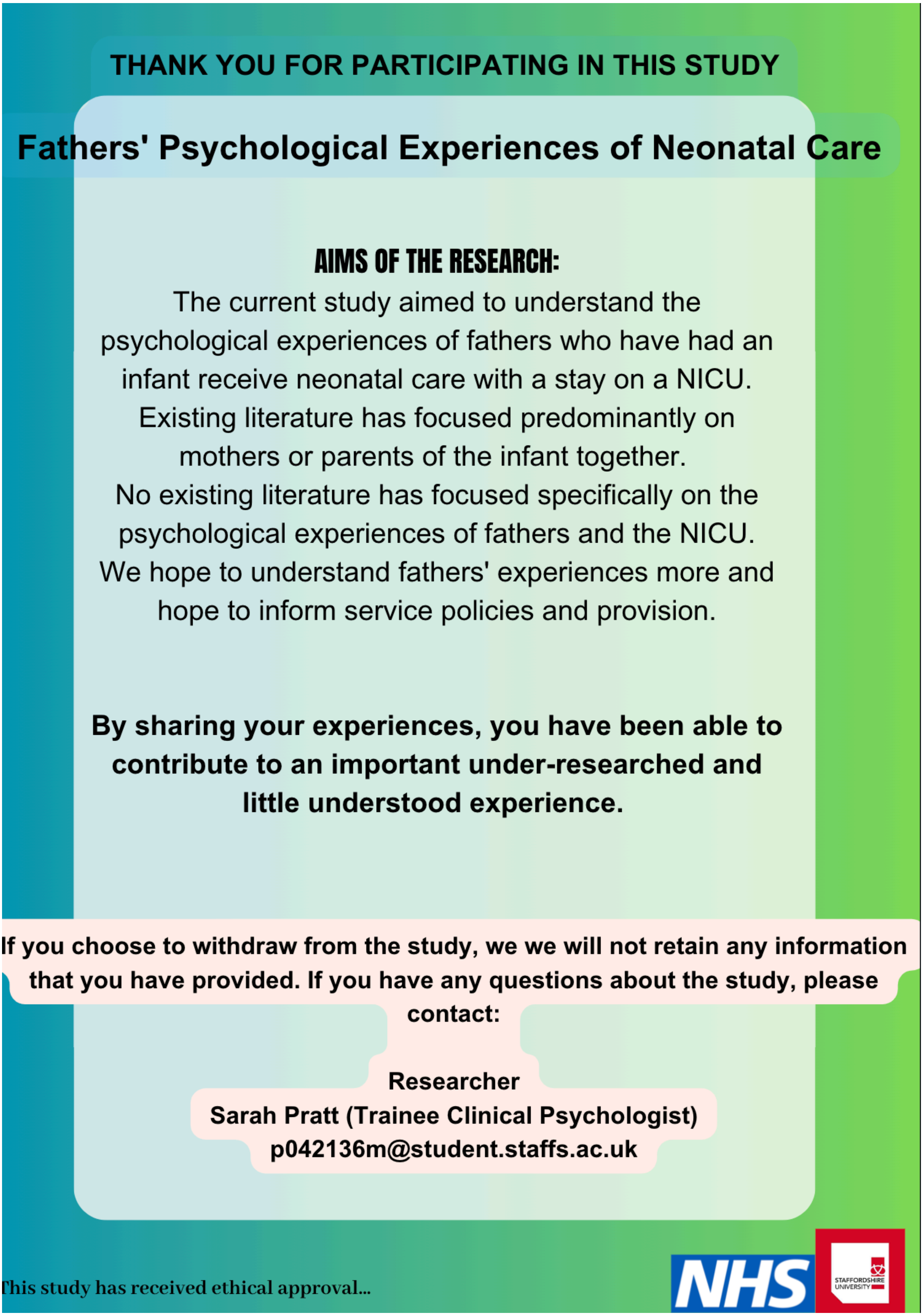
IRAS Project ID: 335201	**Please quote this number on all correspondence**

Yours sincerely

K Stephen

Karen Stephen
Ethics Administrator

Appendix D: Debrief form



THANK YOU FOR PARTICIPATING IN THIS STUDY

Fathers' Psychological Experiences of Neonatal Care

AIMS OF THE RESEARCH:

The current study aimed to understand the psychological experiences of fathers who have had an infant receive neonatal care with a stay on a NICU. Existing literature has focused predominantly on mothers or parents of the infant together. No existing literature has focused specifically on the psychological experiences of fathers and the NICU. We hope to understand fathers' experiences more and hope to inform service policies and provision.

By sharing your experiences, you have been able to contribute to an important under-researched and little understood experience.

If you choose to withdraw from the study, we we will not retain any information that you have provided. If you have any questions about the study, please contact:

Researcher
Sarah Pratt (Trainee Clinical Psychologist)
p042136m@student.staffs.ac.uk

This study has received ethical approval...

THANK YOU FOR PARTICIPATING IN THIS STUDY

Fathers' Psychological Experiences of Neonatal Care

We understand that talking about your experiences may bring up difficult emotions and/or memories for you.

Please contact any of the below organisations/charities if you would like support in relation to things discussed in this study.

Bliss
for babies born premature or sick

https://www.bliss.org.uk/

Tommy's
Together, for every baby

https://www.tommys.org

NHS
Talking Therapies

https://www.england.nhs.uk/mental-health/adults/nhs-talking-therapies/

Mental health support in your local area

SAMARITANS

https://www.samaritans.org/

mind
for better mental health

https://www.mind.org.uk/

Thank you again for your participation

This study has received ethical approval...

NHS

STAFFORDSHIRE UNIVERSITY

Appendix E- Participant Information Sheet

INFORMATION SHEET FOR PARTICIPANTS

IRAS ID: 335201

Title of study

Fathers' Psychological Experiences of Neonatal Care: An Interpretative Phenomenological Analysis Study.

Invitation Paragraph

I would like to invite you to participate in this research project which forms part of my Doctorate of Clinical Psychology. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please, ask me if there is anything that is not clear or if you would like more information.

The research is being sponsored by Staffordshire University, therefore any reference to 'we' means the sponsor and not any NHS site.

Who has reviewed the study?

The North of Scotland (1) Research Ethics Committee has reviewed this study.

What is the purpose of the study?

The study aims to gain an understanding of the psychological experiences of fathers who have had a baby receive Neonatal Care.

We aim to specifically understand fathers' experiences, their thoughts, and feelings, of having a child receive neonatal care. Previous research has often focused on mothers' experiences only, and we know fathers may have different experiences and feelings about neonatal care. Therefore, it is important to understand fathers' psychological experiences of neonatal care.

Why have I been invited to take part?

You have been invited to take part as you have identified yourself as a father aged over 18 years who has had or do currently have a baby/infant receiving Neonatal Care (due to be discharged within the next 4 weeks) in an NHS hospital in England.

You have identified yourself as speaking fluent English.

You have identified yourself as **not** currently experiencing a mental health crisis or receiving support from a mental health service.

What will happen if I take part? What's involved?

Taking part involves talking with the researcher about your experiences of having your baby receive neonatal care. This consists of taking part in one interview which aims to last approximately 60 minutes. You are welcome to say as little or as much as you like about your experiences and there are no right or wrong answers to the questions asked. The interview will take part online. The interview will be recorded via Microsoft Teams with video. If you do not want the interview vide recorded then the interview sound will be recorded only using a Dictaphone.

Do I have to take part?

No, you do not have to take part. Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part, we will ask you to sign a consent form and you will be given a copy of this consent form to keep.

What are the possible disadvantages and risks of taking part?

Talking about your experiences of your child receiving neonatal care may raise some upsetting memories which you may find difficult to manage. Therefore, you are welcome to take breaks during or completely stop the interview at any time, this will not be a problem. Following the completion of the interview, you will be given some information signposting you to appropriate services which can provide further support if you would like to access these.

What are the possible benefits of taking part?

Your participation is highly valued. As there is a lack of research understanding fathers' experiences of neonatal care, your participation will provide valuable insight into how fathers experience their infants' neonatal care. Your participation could potentially influence further guidance into how fathers are supported, and their experiences recognised on neonatal care units.

Data handling and confidentiality

Your data will be processed in accordance with the data protection law and will comply with the General Data Protection Regulation 2018 (GDPR).

In this research study we will use information that you give to us. We will only use information that we need for the research study. We will let very few people know your name or contact details (if you provide contact details) and only if they really need it for this study. We will collect your name for the purpose of gaining consent from yourself to take part in the interview but other than this your name will not be used anywhere else. You may give your contact details if you would like to receive a summary of the research once it has been completed however this is optional. We will keep all information about you safe and secure.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study, we will save some of the data in case we need to check it and/or for future research but we will make sure no-one can work out who you are from the reports we write.

Transcripts of the interviews will be anonymised to protect confidentially. Interviews will be transcribed by the Principal Researcher (Sarah Pratt) only. Audio and video recordings of the interviews will be deleted and destroyed once the transcription of the interview is complete. This will be maintained through the written report of the study and any disseminations of findings. This data will only be shared within the research team.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- www.hra.nhs.uk/information-about-patients/
- Leaflet available from: **www.hra.nhs.uk/patientdataandresearch**
- By asking one of the research team
- By sending an email to the sponsor's Data Protection: dataprotection@staffs.ac.uk

Data Protection Statement

The data controller for this project will be Staffordshire University. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under the data protection law is a 'task in the public interest'. You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

What if I change my mind about taking part?

You are free to withdraw from the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You are able to withdraw your data from the study up until 6 weeks after the initial interview has taken place, after which withdrawal of your data will no longer possible due to the data being anonymised and included in the final report of the thesis.

If you choose to withdraw from the study, please contact the principal investigator, Sarah Pratt (email: p042136m@student.staffs.ac.uk). We will not retain any information that you have provided to us as part of this study.

What will happen to the results of the study?

Findings from the study will be reported in an empirical paper to fulfil the requirements for a Doctorate thesis. Potentially, the results could be published in a research journal which could be available to view by the public. However, all data will be anonymised to ensure no identifiable data is included.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Principal Researcher:
Sarah Pratt- Email: p042136m@student.staffs.ac.uk

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor or the Chair of the Staffordshire University Ethics Committee for further advice and information:

Professor Nachiappan Chockalingam
Email: N.Chockalingam@staffs.ac.uk

Complaints:

PALS at University Hospitals of North Midlands NHS Trust: Patientadvice.uhnm@nhs.net or telephone: 01782 676450.

PALS at University Hospitals of Derby and Burton NHS Trust:
uhdb.contactpalsderby@nhs.net

Thank you for reading this information sheet and for considering taking part in this research.

Services that can offer support should you wish to access them:

Bliss https://www.bliss.org.uk/

Tommy's https://www.tommys.org/

NHS Talking Therapies https://www.nhs.uk/nhs-services/mental-health-services/

Samaritans https://www.samaritans.org/ Call: 116123

Mind https://www.mind.org.uk

Appendix F- Consent Form

Consent Form

IRAS ID: 335201

Participant Identification Number:

Title of study: Fathers' Psychological Experiences of Neonatal Care: An Interpretative Phenomenological Analysis Study.

Name of Researcher: Sarah Pratt (Trainee Clinical Psychologist)

Participation in this research is voluntary

Please initial in the box next to each statement

1. I confirm that I have read the information sheet dated 02/03/2024 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I can confirm that I am **not** experiencing a mental health crisis and/or currently receiving support from a mental health service. ☐
4. I understand that my participation is voluntary and that I can refuse to answer questions and that I can withdraw from the study at any time up until 6 weeks after the initial interview has taken place, without having to give a reason. ☐
5. I understand and agree to the interview being audio recorded. ☐
6. I understand that I have the choice to have my interview video recorded. If I decline this then it is my responsibility to turn my camera off during the online interview. ☐
7. I understand that the information I provide will be used for a research thesis conducted by Sarah Pratt and that information I provide will be anonymised. ☐

☐

8. I agree that my anonymised information can be quoted in research outputs.

9. I consent that data collected could be used for publication in scientific journals. ☐

10. I understand that any personal information that can identify me- such as my name, will be kept confidential and not shared with anyone other than the researcher and their academic supervisor. ☐

11. I agree to take part in the above study. ☐

Please retain a copy of this consent form

Participant name:

Signature: Date:

Researcher name:

Signature: Date:

For more information, please contact: Sarah Pratt (Trainee Clinical Psychologist) P042136m@student.staffs.ac.uk

If you would like to receive a copy of the summary of the results of this research upon its completion, please leave a contact method below:

Appendix G- Interview Schedule

Interview Schedule

Setting up the interview:

I am interested in talking to you today to find out about your experiences, particularly the psychological experiences of having your infant receive neonatal care.

Please take as much time as you need to think and respond to questions asked. You are welcome to say as much and as little as you like about your experiences, please remember there are no right or wrong answers, I just want to understand your individual experiences. The interview should last for approximately 60 minutes.

If at any point you want to pause for a break or stop the interview, please do let me know. If you do not feel comfortable letting me know, we can think of an alternative way of letting me know, together now.

I won’t be able to offer any professional support after the interview however I will provide you with a debrief form that will have the details of services you can contact for further support if you wish to access these.

Do you understand this information or would you like anything clarifying/repeating?

Do you have any questions before we begin?

Please ask me to repeat any questions during the interview if you need.

Questions

1. Please tell me about your infant who received neonatal care and the circumstances that led to them needing this?

   Prompts- Thoughts and feelings during this time.

2. Talk to me about your experience of being a father of an infant who has been in neonatal care. What was it like for you at the various stages of the process/journey?

   Prompts if needed: Pre admission, Birth, Admission, Stay, Discharge, Post-Discharge (thoughts and feelings during each stage).

3. Talk to me about your connections/relationships with other people whilst in neonatal care and the impact these may have had on you.

   Prompts if needed: Other parents/families, staff, support groups

4. Tell me about your feelings and experiences of the neonatal environment.

5. Talk to me about any support you received or did not receive, during and/or after your infants stay.

6. Is there anything that we have not discussed that you would like to talk about? Any other factors that you think have been important/ had an impact on your experience?

Ending and debrief:

How do you feel at the end of the interview?

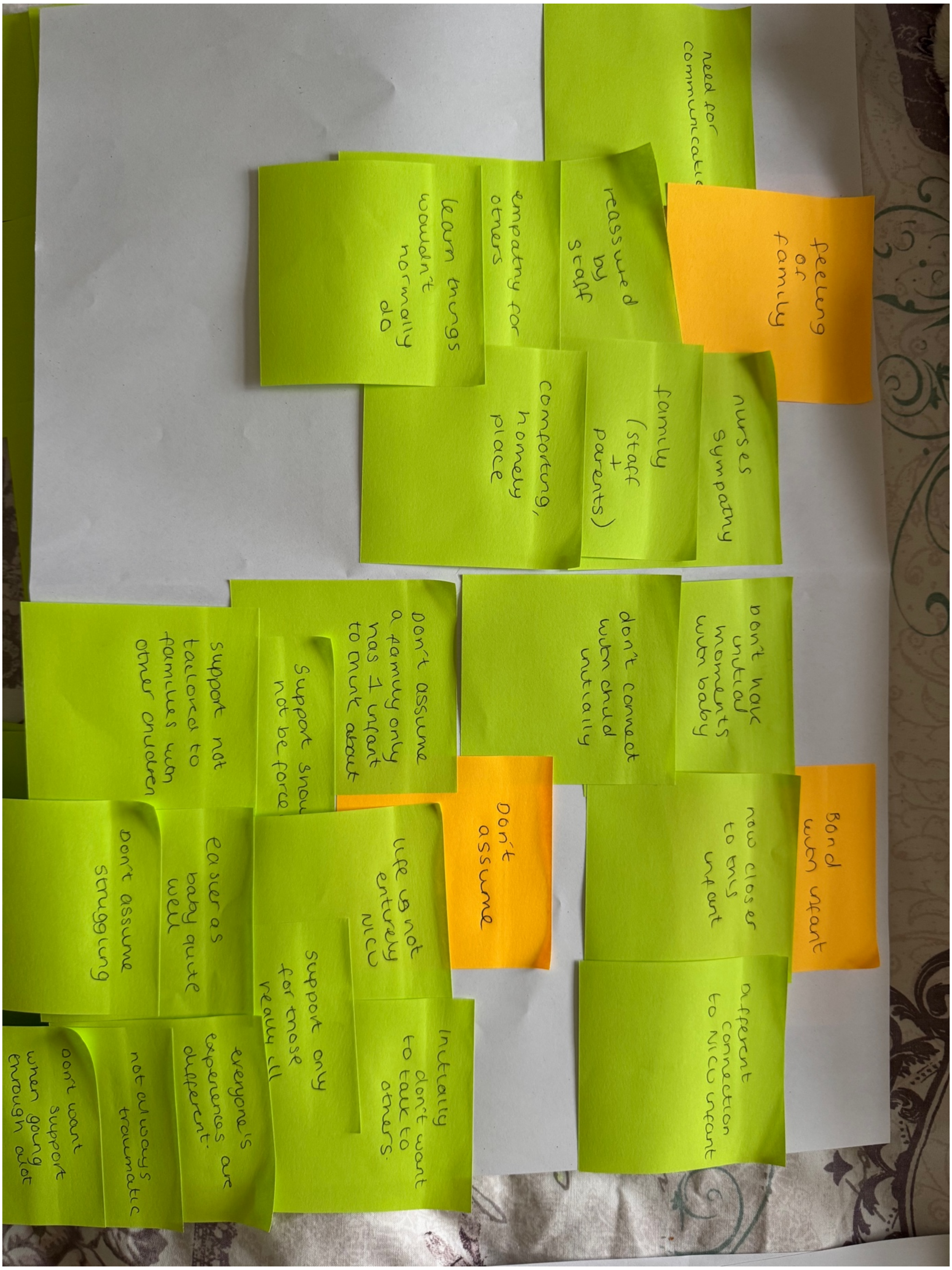
Do you feel able to access support should you wish?

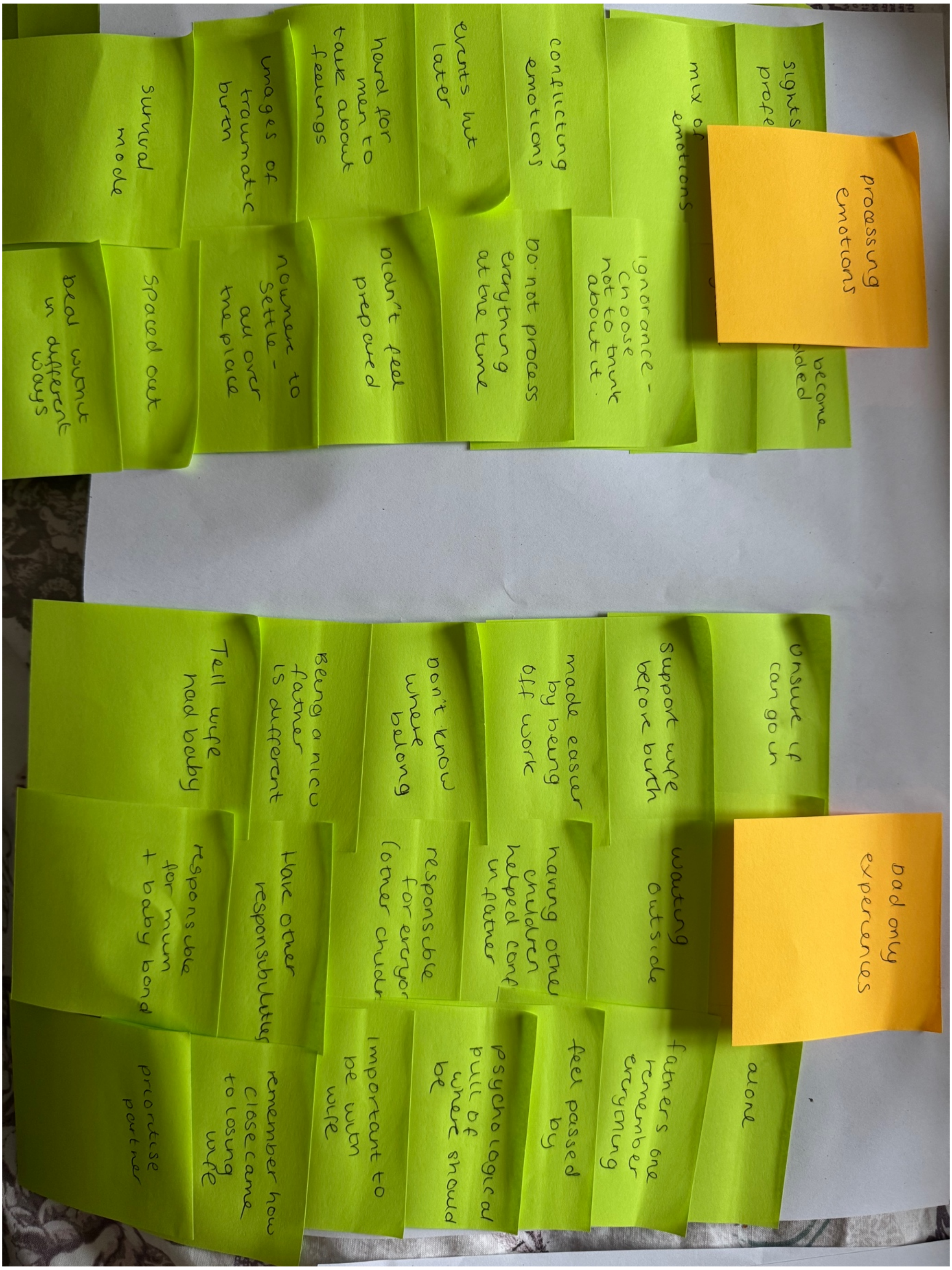
Any questions?

Appendix H- Example annotated transcript for Curtis

Parents have to prepare that their babies could die however much that they do not want to	like I said, weeks experience, probably more like week 19 of gestation that we have to prepare, that we could lose them.	Had to prepare that twins could die
	I: Hmm.	
Parents feel vulnerable on the NICU when experiencing a range of emotions	P: So there was an element of, the vulnerability I think for us certainly you know as parents, you never you never want to think about the worst case scenario.	Felt vulnerable as parents
	I: Yeah.	
Father felt the care on the NICU was good and well organised, feeling cared for on the NICU helped their journey Father described his experience as an 'emotional rollercoaster'- a likening the experience to many ups and downs, surprises and unknowns along the way 'swept up in a whirlwind'- fathers feel they do not have control over what is happening- whirlwinds can be disorientating and damaging Parents at time have moments of realising the severity of the situation they in- possibly are not always able to realise the severity of the situation	P: And unfortunately, with our daughter, we we suffered it anyway. But. We I don't know the care the care is so professional is so. It's so well engineered, you know, even at where the twins were born and obviously taking them to the big tertiary hospital where I used to work for seven years that it's it's a level of and quality of care where you as the parent, you know you're an integral part of it, but you're so well looked after and things are just done when they need to be done. You don't mess around with kids that. You know the emotional rollercoaster started, but it was all obviously a bit of a whirlwind that you kind of just got swept up on really or swept up in. But yes, it was it was difficult, I remember sharing kind of messages with Amy's mom probably who took her into hospital. You know, the twins have been born and you kind of get these releases of reality like, oh, wow. OK, this is pretty serious now, and they're obviously very critically unwell, which necessitated their need to be intubated and ventilated. And there were tiny, which is what you'd expect at that destination age and having.	Care is well engineered- from caring for the infant to caring for parents. Parents felt cared for Emotional rollercoaster Whirlwind- swept up in, feeling of being out of control, no choice what happens? Releases of reality- suddenly realise how serious the situation is
Parents are asked difficult questions early on and have to make difficult medical choices that other parents do not	P: Two, but yes, we had some pretty frank questions pretty early on about. You know, how much do you want us to do for them? And we said absolutely everything bar. You know, if they're going to be really, terribly unwell as a result of the medical intervention, then that's something we don't feel so keen about.	Had difficult questions asked to them early on

Appendix I- Example PET creation for Edward




processing emotions
sights profe
mix of emotions
become
dded
conflicting emotions
events hit later
hard for men to talk about feelings
images of traumatic birth
survival mode
ignorance - choose not to think about it.
Do not process everything at the time
Didn't feel prepared
nowhere to settle - all over the place
spaced out
Deal with in different ways
Dad only experiences
Unsure if can go in
Support wife before birth
made easier by being off work
Don't know where belong
Being a NICU father is different
Tell wife had baby
waiting outside
having other children helped conf in father
responsible for everyon (other childr
Have other responsibilities
responsible for mum + baby bond
alone
fathers one remember everything
feel passed by
psychological pull of where should be
Important to be with wife
remember how close came to losing wife
prioritise partner

Appendix J- Table depicting PETs across all participants and GETs

Participant	**Personal experiential themes and subthemes**				
Aaron	The journey of emotions • Confusion • No escape • Worry for everyone • Scary environment	'It's my duty' • Focus only on family • 'Don't show emotions' • Need to protect- reassure, take away pain • Men are not vulnerable	A different kind of loss • Loss of journey expected • Loss of memory making • Baby misses out	Impact of others • Sharing experiences • But don't want to talk to people too?	The positives • Learn to be a parent
Billy	The unknown • Not knowing what might happen next • No one understands	Different reality • Things are strange • Alien environment • A different journey to others • Loss of traditions	The raw emotions • Never ending fear • Delayed processing of emotions • Takes a huge toll	Life as a dad on the NICU • Am I a Parent? • Don't show emotion • Don't get a break • excluded	
Curtis	Flexibility of support • Need a choice • Staff support • Extended family	Role of a NICU dad is different • Useless • Bond with baby • Don't feel like a parent • Responsibility for partner • Feel in the dark	Lack of normality • Other people responsible for your baby • Want to see baby as normal • Want to make normal memories	Living in uncertainty • Constant ups and downs • Uncertainty continues after stay • Madness • No control • Don't think about it	Grief on NICU • Vivid memories • Prepare for the unthinkable
Darren	It never leaves you • Affects further birth • Forever with you • Can't process it	The losses • Bonding • Am I a Father? • Normal things lost	Emotional pain • Isolation • Surrounded by distress	Positives • Time to adjust • Staff support	

		• Life changes	• Sudden changes in emotions			
Edward	Processing of emotions • Conflicting emotions • Survival mode • Images and sounds stay with you • All over the place	Dad only experiences • Work • Don't belong • Different jobs • Having siblings • Only one to remember	Feeling of family • Communication • Home • Empathy	Bond with infant • Different connection	Don't assume • Life is not entirely NICU • Is it traumatic? • We have other responsibilities	
Freddie	Identity of a Dad • Multiple worries • Loneliness	A change in you • Proud • A different parent • New normal • New couple	The impact goes further than the NICU • Impact of families around you • Memories stay with you • Loss of experiences	The whirlwind • Don't think about it • Chaos • Range of feelings • Sudden realisation	Importance of support • Informal support • Having someone similar • Community	
Gavin	Feeling proud • It's the small things • Sense of achievement • A better relationship	NICU stays with you • Relationship bonds • Constant panic • Difficult emotions	It's not just your journey • Emotional impact of other families • Separating self from others	What makes it easier • Managing responsibilities • Support • Knowing what is going on • Staff	dad's role on the NICU • Need to be included • Treated as equal • Can't think about self	The known & the unknown • Things change quickly • Confusion • The gem or curse of previous experience
Harry	Emotional rollercoaster • Constant changing of emotions • Become desensitised • Waves of realisation	Family & Camaraderie • Need for staff • Want to help others • It's a family • Indebted	The after effects • Bond with baby • It changes you • It never leaves you	It's a dad's experience • Search to be included • Face a different reality • Different responsibilities		

	- Contrasts in feelings	- The sharing of experiences	

Group Experiential Themes (GETs) key:

🟨 The emotional roller-coaster

🟩 The hidden not heard experience

🟪 The people around you: help or hinder?

Appendix K- Supplementary participant example quotes

GET	Subtheme	Quotes contributing to theme
The emotional rollercoaster	1.1 A thunderstorm of emotions	Aaron: “That obviously was panic. Then 'cause in our heads. We're just thinking. Well, it's too early, but I don't know. This is our first child you see. We're just on the understanding it's in there for nine months and that it comes later on”. Aaron: “So I was stressing that week, I was quite anxious for stuff that week. Umm. Don’t know how to describe how I'm feeling.” Aaron: “You're just thinking something's going wrong. Something's going wrong kind of thing because you're panic because you see the incubators and some of the babies are tiny” Billy: “So there were, there must have been, I think 14 nurses or anaesthesiologists? Like all these different sort of medical titles in the room with us.” Billy: “What turned out to be a really, really awful time in our lives, to be honest.” Billy: “I haven't been back since and I don't want to. And I realised not many people know what Nicu is, to be honest. It's a really bizarre place.” Billy: “You you feel like you have to rush back and just in case they aren’t alive when you when you come back and yeah, I I can't. I can't really. I can't sugarcoat it any more than that. Like they might not be alive when you come back.” Billy: “I think their physical appearance is quite scarring when they were first born because they didn't really look like babies” Curtis: “There wasn't much time to prepare at all, the emotions.” “Oh, it's gonna be tough now. The emotions were. Were an unknown.” Curtis: “You know the emotional rollercoaster started, but it was all obviously a bit of a whirlwind that you kind of just got swept up on really or swept up in” Curtis: “you kind of get these releases of reality like, oh, wow. OK, this is pretty serious now”

	Curtis: “what I witnessed that difficult intubation because again the anatomy is so small was was difficult to kind of watch as well as me thinking about my partner and her needs” Curtis: “you know, just to try to compartmentalise it all because it's just it's mad really” Curtis: “You're just whipped up in this. This this I don't know this like thunderstorm of. Just things that are totally out of control.” Curtis: “you know on the continued journey of uncertainty was always the best word, the best I think word that we stumbled across with regard to an NNU journey is uncertainty. We live in this sense of unknown” Curtis: “the perfect storm of you're totally out of control. You don't really know what to feel, when to feel it. You feel vulnerable. But it's just masked by being wrapped up in this, this huge transitional period.” Curtis: “And your emotions change, you know, in parallel to all of those three parts of that journey.” Darren: “It was like you and your own kind of isolated little world and not really knowing what's kind of going on.” Darren: “NICU, It is grim. So grim is in, not necessarily like the environment or the people, but the. Surrounded by these little kids, who could be dying” Darren: “yet the sort of thing the things that always stood out to me were like the darkness, the noise and the like. Peace, the peacefulness of the people” Darren: “I didn't know what was going on. I didn't know if I was going to walk in. He was like dying or or what?” Darren: “You come from what's meant to be like a really joyous thing in a bright open area room with your new child, your wife. To that kind of, you know, environment quite quickly without any kind of preparation or explanation of what you're going to be going into”

	Edward: “It's interesting, really, isn't it? It's. I think in a situation like that you'd your adrenaline kicks in, doesn't it? And it's very much fight or flight.” Edward: “you know, it's everyone's experience is going to be a little bit different. But I think, yeah, sometimes we can over traumatise things in a way I think.” Edward: “Yeah, it was traumatic. But, you know, it was kind of managed well and you could rationalise that things were getting better so.” Freddie: “I don't think we, I really thought about it until like until he was born and then kind of when you're thrust upon in that situation kind of is a kind of a whole heap of things” Freddie: “So it is a bit of a whirlwind” Freddie: “I don't think anything can re prepare you for when you're actually when you're actually in” Freddie: “So kind of within like within that first hour like after kind of they you kind of watching them them tubing him all up and everything like that and then you go to surgeons coming along with consent forms and drawings and this is what we're going to do and all that sort of stuff as well. So it was that first couple of hours there's quite a lot to take in.” Freddie: “it's just kind of running on adrenaline because it's obviously like the happiness of having a baby as well. But then and then obviously, like knowing what was going on” Freddie: “Yeah, it's scary. It's chaotic. You're kind of all over the place” Freddie: “Like it's I think it's scary. It's overwhelming just because of what the place represents and everything that you see around you.” Gavin: “what the hell is going? What the hell happens now what? What, what sort of sort of happened? So was always a bit of confusion?” Gavin: “oh, my God, they're going to die. Like, what's going to happen.” Harry: “sort of rushed me through the hospital the wrong way, through all the staff doors. And it was like, this is weird. This is very odd”

		Harry: “I could have just fallen apart there and then. And it's like you're there and you've got a lump in your throat.” Harry: “just such a rollercoaster. Some days you could go in and it'd be like, oh, we've done this with him and you'd be dead happy. And then the next minute, something had happened” Harry: “So some days you want to go and fighting 'cause we've not really got anywhere. And then other days you were happy because something had happened and we'd gone in the right direction. And then the next day you could be bloody crying because you're going backwards. “ Harry: “It's like you were so hyped for everything happening and everything was just so intense. It was like you were just running on adrenaline.” Harry: “I don't think it quite dawned on me how sort of serious everything was going to be”
	1.2 The NICU experience lives on	Aaron: “One thing you do worry about when you leave NICU is, how vulnerable he is” Billy: “So I think in terms of like mental health impact it it maybe didn't. Maybe not at the time. Realise how much it did impact us, but.” Billy: “I think. Psychological toll the emotional, the emotional exhaustion. Is not really felt until afterwards,” Billy: “I think I think because I was no longer as emotionally busy, you could actually take a minute. I realised that I didn't, I no longer knew how to have a break because I hadn't had a break. Well, for all the pregnancy I'd spent all my time worrying.” Billy: “it's probably about three years worth, of like horrible life and horrible sort of mental experience. So it did. It did take a good sort of three years or so from start to finish before I consider myself normal again,” Curtis: “Your brain is very good at forgetting traumatic events and I don't really remember too well those first hours.” Curtis: “Then there was a real emotion of. I don't know, like emptiness or just loss, but equally you couldn't live in that moment for very long because Max was next door and we have to go in, you know, straight back to him and make sure he was OK”

	Curtis: “Do you know what have I got any space or time here to grieve or to accept that? I've just lost a daughter” Darren: “convinced they were going to kill my wife by accident or she was going to die and I think. Thinking about it I don't know if it was because of the experience that we'd had with ****, that I was just so overwhelmed with anxiety that it was gonna happen again” Darren: “And then just being in that environment again. Was really bad. I don't think I’ll ever get over that” Darren: “obviously I've cried loads talking to you, so it's definitely affecting me.” Edward: “hits you probably later. Really. I think at the time you don't process everything and you know you just. You just do what's best for people” Edward: “It was me that actually. Remembered a lot of the room and to be honest, it's me who remembers a lot. So I remember a lot more than she does of everything, you know. Long term. It's yeah, because I saw everything” Freddie: “I don't think we're quite prepared for the like kind of what it takes out of you physically and mentally, just there every single day.” Freddie: “the kids that pass away that stuff kind of really lives with you really lives with you.” Freddie: “It's kind of like you kind of conflicted feelings in that and then when you finally get the the the call that OK right you can go home. It's kind of even more scary. 'cause. You're like crap. There's actually gonna be no one. It's just gonna be like, like, it's just gonna be us.” Gavin: “because within about two days, you know he went blue basically. And and we thought he was dead. The poor thing. Then we had to rush to hospital again. So it was. It was like that was, that was”

		Harry: “sort of said to him that it's one of them things that once you've been in there, it's ingrained in you. I mean, I go to all the meetings and we raise money now and stuff and I should do more and more for them because, you know, I could never ever pay the debt. I owe the place” Harry: “I think while I was at the unit because you were there all the time and you got so many tasks questions and you know, you could constantly sort to bounce off somebody about things that when you came home it was sort of a little bit like. Oh. Oh, I don't know” Harry: “like, is he all right? I have to go and check on him constantly. And it really, really like eats at my sleep because I just don't shut my eyes. I lie there listening to him breathing. “ Harry: “There's there's definitely some underlying, you know, whether you want to call it PTSD or whatever it it it definitely affected me. And I think it's going to take a long time for it to, you know, dissipate off. “ Harry: “Even now it still gets me, you know, like sitting, talking about it like this for long periods. You can feel it proper getting to you. It definitely chokes me up sometimes. “
	1.3 Grief is multi-faceted: from loss to growth	Aaron: “you know, when you do these little photo shoots with like Christmas pudding hats on and stuff like so they were having that, but we couldn't. So every time we went to see him, you can't bring him home” Aaron: “It's almost like he was kind of. It's gonna sound selfish, but kind of like missing out, you know, because they're all doing these kind of things. But you can't because you've got to leave them there.” Aaron: “I suppose you're pictured in your head, right? We're gonna go. And she's gonna give birth. We'll be walking out with the baby carrier and she'll take a picture, annoying stereotypical social media baby births, but obviously ours was quite different.”

	Aaron: “I think if I should have just gone in, gave birth and was going home 3 hours later, that would have been completely different and you'd be like, what do we do now kind of thing?” Billy: “Obviously people always say like. Oh, that beautiful baby is and how cute it is and stuff like that. But I think when they're that premature, they're really not. You just don't. But I just didn't see how they would survive” Billy: “Think one thing I've skimmed over is the impact of coming home without them. Obviously no parents really go through that. So I think that was one of the worst experiences I've ever had, and I'm sure my wife would say the same... we got home and they decorated the house, and it was a really big reminder that they weren't here.” Billy: “We'd obviously had like a 7 month pregnancy where they had been at home, so to speak, and suddenly they weren't. Suddenly we were back to just us two” Darren: “You felt more supported to. In case there was a problem, I guess you weren't on your own. You weren't immediately thrown into. I've been at home with a baby crying, not knowing what to do” Darren: “So I think reflecting back on on that, it was obviously a negative experience, but I think it's it's come out to be a positive thing thinking about it because we had that period of time with them supporting us” Freddie: “I think you look around at people in like other people in your family as well that are just kind of like they're they've kind of had kids in their home straight away and they kind of just get back into the normal things. And so I think you just have a different norm to.” Freddie: “kind of a big sense of achievement” Freddie: “although it's not a nice thing to go through, I think it it does give you, I think it give you a very good grounding for parenting” Freddie: “I think it's made us better. I think it's made us better parents” Gavin: “I'm sort of proud of me and my wife that we sort of got through it the way we did.”

		Gavin: “it's like here I have a baby you know go and deal with that we we we didn't have that like what do we do because we've been trained” Gavin: “it is massive and that has helped for me and my wife. You know, we've shown we can work as a proper team which you need to as your parents. So that's made us sort of more, more stronger as a couple as well I think.” Harry: “It's not one I particularly perhaps would have wished to go on, but having now gone through it and come out the other side, it's a place I will never forget. “ Harry: “Obviously it's very harrowing and it's a lot of hard work, but the outcome is, you know, when you see him, it's fantastic” Harry: “I wouldn't wish it on anybody. But to have met all them fabulous people and watched them just literally turn a miracle every day. You know, and it's not just our miracle”
The hidden not heard experience	2.1 My duty as a man	Aaron: “So then obviously I've got to try and kind of keep it more positive, but I I don't. I don't mind doing it like it didn't really affect me too much. I’d like to think I'm quite a positive person” Aaron: “But I've I've gotta then try and pick her head back up. 'cause at the end of the day it should be a nice experience” Aaron: “It's the man's job to look after everybody, and it's my job to protect him from everything. So you guessed. You kind of feel like although I was just sat next to him. I was. I was there protecting him.” Aaron: “Well, I just kind of just a man's role isn’t it stereotypically so in my head you're thinking, right? I've got to hold things together. It's my job here.” Aaron: “Like even days when I was like, knackered or literally just didn't have a second. I'd you'd I'd still force myself to go 'cause I. I just felt it was my duty to be there for him, even if it was just sitting next to him.”

	Billy: "I didn't get upset because I think my roles are this, like, subconsciously was to reassure my wife and to make her feel like everything was going to be OK" Curtis: "it's my duty to look out for her and everything that she needs as well as the two little ones, and it is just literally you could not create a more perfect storm of trying to manage all of these hugely kind of complex events" Curtis: "actually I feel I felt emotionally quite. I think withdrawn from the fact of I was then sort of surplus to requirements of it. I needed to maybe be there for Amy, but equally I could do so much less" Curtis: "I couldn't really do anything. I didn't feel like I was much use." Curtis: "I I just do a lot. I never sit down. I don't. I don't stop. And I feel like that's part of my self preservation that I just. You know, with my loss and what happened, I just keep going. I don't think about it." Edward: "So I'm, you know, Dad, waiting around outside" Edward: "I suppose if it was my first child, I would have been, you know, horrified, because, you know, your first child kind of hits your quite hard, doesn't it? And it's you really don't know what to do, whereas in this situation, I think I could kind of rationalise, you know, what's the best thing to do here? And, you know. Give myself a bit of time to say that. Well, you can't do everything." Edward: "As a dad, it could be quite easy to get kind of passed by in terms of what's happened and what they've witnessed, because you know, physically they should be OK in that situation" Freddie: "you just kinda just kinda took it in my store and kinda had to. I think that's the key thing really. Kinda not really got any other choice." Freddie: "But then in that moment, like, none of that actually matters because you just get on with it and and yeah, something you have to do."

		Gavin: “the way I dealt with a lot of stuff with both kids was just, like, 100% focus on that. Don't care about anything else. Literally couldn't give a **** about anybody else. In the nicest possible way.” Gavin: “you could clean that and even just silly things like that makes a massive difference because there's nothing worse in any case of sitting there like a bit of a spare.” Harry: “You're just obsessed with doing everything and. I was like pushing into the feeding and getting into that”
	2.3 The unique experience of a NICU dad	Aaron: “I guess you kinda just think because that's my son, I need to be there for him all the time, even though essentially I can’t do anything. I was just sat with him so.” Billy: “But it just, I think helplessness is the the main word, to be honest, because there there is really nothing you can do, except worry.” Billy: “But yeah, it was just quite a bizarre time to have to ask permission to more or less look after your own child.” Curtis: “I think as a parent you hugely just instil your belief and trust in someone else to look after the health of your child and that is, that's quite special” Curtis: “so you feel like you're in the dark a little bit. You obviously are just watching on. And and a little bit helpless, if I'm brutally honest.” Curtis: “not at any point would I have identified that I had the little ones, I was in their company in a room where I was not really able to get anywhere near them. You can't touch them. You can't parent them.” Curtis: “Just have some. Real time with her, where she was now just a little baby and you know a bit very, very small. But she didn't have any lines or tubes or anything attached to her. And we could just hold her and and do the things that in reality you always want to do as a parent. And that felt that felt really nice to.”

	Curtis: “Even though you know she's unfortunately passed away. But it was the first time you really felt. You could hold her and just love her like you wanted to.” Curtis: “And the more and more time that you're there, the more and more parenting you can do for your child, which is a little bit far removed from, you know, parenting in the traditional sense” Darren: “I just couldn't see him and I was just stood staring at the door waiting for them to come get me.” Darren: “I suppose I hadn't really had a chance to kind of experience being a father or dad at that point” Darren: “so we didn't really get a chance to go hold him, give him a hug, kind of that sort of stuff until he was in that kind of second, less intensive care bit. And I suppose that's where that kind of father type bond thing really kind of started, I guess.” Darren: “it kind of felt being a bit more like a normal parent. In terms of, you could hold hold your child” Edward: “I think you know in some ways it probably helped me to bond a little bit more with **** than my other children because it was just me.” Edward: “he kind of has like a little bit more connection with me and is that because, you know, in the first few days of his life, he saw more of me than he did his mum.” Edward: “We are soft with him. So, you know, he is like a precious little baby. And we're very like. You know, we we are a little bit softer with him than the other two” Freddie: “we were almost in kind of a fortunate position compared to everybody else because we could we could pick him up whenever we wanted, we could change him” Gavin: “kangaroo care and and all that sort of stuff was was that was really good and it was it was great for a dad that you could you could do stuff I think weirdly you know”

		Gavin: “I could feed the baby all the time. I could change the nappy I could, you know, help them change the tubes. And so I felt like I was being useful whereas none NICU dad’s can’t if mum is doing the normal breastfeeding” Gavin: “So it was like a real team effort, which I think. It's helped you know from a dad, from a dad perspective” Harry: “And leaving him was really difficult. That was heartbreaking.” Harry: “I don't love any of them anymore or any less than the others. But certainly the connection with Rafe was like. Instant and it was powerful” Harry: “you know, you could even find me on a dark night sat at the side of his incubator reading like Fluffy Bunny Tail or that's not my rabbit”
	2.2 The strain of competing roles	Aaron: “I was speaking to their dad one day and he was saying pretty much that the same stuff as me about feeling he was still working. And he's having to do all that, do the house and then come to hospital every day. And it's hard.” Aaron: “But like I say, after that you just feel guilty. But by the time I've gone to work. Go and see him doing the dogs, blah, blah, blah. Then you'd be physically tired. You know what I mean? So it was like you was getting drained from both mental and physical.” Aaron: “I suppose just stay worrying that he's gonna be OK and that Megan was alright. Kind of thing. Then obviously, you've constantly got people messaging you and there's no escape from it.” Billy: “It was chaos, to be honest. Like you, you wanted to be in both places at once.” Billy: “you're so emotionally invested and busy, but you don't really have time to think about yourself or your job, your house or anything like that”

	Curtis: “there was some very stressful moments of trying to manage. Work. My guilty conscience sort of saying, you know, I can't really do much with my son and supporting my my girlfriend, but I should be at work” Curtis: Trying to to find my own comfort from being off work or the guilt that was assigned to it to actually being there and being supportive for my. My family, which was obviously far more important, but I struggled to see it.” Darren: “the thing that's always kind of stood out to me that I've always kind of remembered and kind of reflected on is standing in the waiting room downstairs.” Darren: “I was concerned with with obviously why they were taking him. But then also because I hadn’t seen **** since they'd wheeled her off.” Darren: “there's definitely like a a kind of who should I go to because she's upstairs. He's downstairs. And I think I think I kind of thought she was probably being looked after upstairs. By adults and people. Whereas Harry downstairs doesn't have anyone” Darren: “The whole kind of week, certainly the early part of the week, just kind of merged into one thing where the only thing you could kind of focus on was your child being alive, your wife being alive and you being alive, and then nothing else really mattered.” Edward: “Psychologically. It's like, what do you do? You know where I'm meant to be in that situation.” Edward: “you know, telling her she's had a baby. And I have to tell that about five or six times. To just because she's, you know, she's been through a lot of trauma” Edward: “I was worried about my wife and that's that's probably the overarching feeling I had at the time. Was I was worried that she was going to die. And that that was my first concern.”

	Edward: “Because I had other places to be, I've got, you know, the two older children to get to school or wherever as well. So you know, you know, managed to sort out family to help me out and those kind of those kind of things.” Edward: “what we'd probably do is I’d sort my wife out for the day and say, have you got everything? Then I'd go around. Doing whatever else needed to be done for the family and you know, popping in” Edward: “So I think, yeah, I think in it's a different challenge when you've got you know, more children. And yeah, I think sometimes you've just got to limit your time. You know, you can't spread yourself too thin. I think that's the important thing really.” Freddie: “obviously you separate from your partner as well. And then you've got the and you kind of like worrying about two different things at the same like the same at the same time” Freddie: “You're by yourself it in it in a way. And you can also feel, feel a bit helpless as well because you're like, where am I supposed to? Where am I supposed to go? I can't be in two places. Like two places at once” Freddie: “Confliction of like where you're supposed to like where you're supposed to be, you're supposed to be like with the baby. You're supposed to be with your wife like that. I think that's probably the most difficult thing.” Freddie: “as my wife's coming around. She obviously wants to know what's going on. And then you're, like, trying to talk to the doctors and keep someone else informed as well” Freddie: “the best time is to happen when you've just got, when it's your first child because one you don't know, you don't know anything at, you don't know anything else. And secondly, kind of your responsibility, you can focus all your attention on that one child that's in hospital.”

		Gavin: “you’re dad who has to go back to work then you know I can imagine that that becomes real difficulty because you know you that you haven't got that support around you you just frantically trying to live your life and look after your wife and kid and you know and probably sort the house out as well.” Harry: “I'd had a week off to have, my older son, which was harrowing. Anyway. That was awful, because obviously he'd literally had mum, mum, mum, mum and then suddenly she wasn't there, so we had some horrendous times with him.” Harry: “You don't know what to do, where to be” Harry: “Then I could hardly talk. They were asking stuff and you just couldn't answer it. 'cause. I just couldn't get the words out”
The people around you: help or hinder?	3.1 Staff make a difference	Aaron: “but the hospital staff kind of weren't worried if you know what I mean. So, they did help to settle you down in a way.” Aaron: “But quite often when we went for an appointment, you could you could see there was understaffed 'cause, there was all running round like headless chicken kind of thing and the queues are massive and obviously people are getting hot and bothered.” Aaron: “Don't wanna say annoyed me but you are getting mixed messages? So in a time when you're already stressed, you'll be constantly questioning everything like what they're saying. Do they know what they're doing?” Aaron: “One day we got there and we walked into where he was the night before and his incubator was empty. So I instantly like what's going on here. Has he died? Which first thing that's popped in your head, but all that happened is they moved him and not told us.” Billy: ”all the nurses do an amazing job because they, they make they made you feel Like these little victories were really huge steps”

	Curtis: “I think you just have to trust in the system. You have to believe you know what you're being told that these people are doing their utmost in the best interest of you as the parent.” Curtis: “They were looking out for you. They're really invested in you and understanding kind of can we do anything to support you because and the more you know” Curtis: “they're just incredible and that is very reassuring, gives you huge comfort and Peace of Mind that you know you can sleep at night and the knowledge that the children have been well looked after.” Curtis: “That's essential because it really lowers your stress levels when they're already through the roof anyway. That you can, you know, you can pick up the telephone or someone will answer it and they'll give you an update, you know, straight away as to as to how you're getting on. And they really know and they care.” Darren: “And not saying necessarily why they they took him away, I think was concerning” Darren: “Just maybe like a clearer perspective of why they were taking him and how poorly he really was. Because I think otherwise. You end up kind of making assumptions,” Edward: “I think, you know, they were quite they were quite good at supporting me in that in terms of, you know, they understood that I couldn't be there all the time” Edward: “I think sometimes it's taking the time to explain to them what's going on.” Edward: “that little bit of empathy I think, which is, you know, we talk about it all the time. But if it's your job, day in, day out, it's quite easy to lose that with families. So, yeah, that that was always appreciated.” Freddie: “The nursing teams are fantastic like they they go above and beyond and like. Make you feel like it's actually your kid that their kid they're looking after” Gavin: “the nurses would say, oh, the baby is really lazy. He won't breathe. And that that used to **** me off a lot because. you know babies can't be lazy.’

	Gavin: “they should tell you what's going on. So you can understand it yourself.” Gavin: “I mean all the staff were were fantastic there. You know, I can remember, maybe not by name, but certainly by face” Harry: “I think one of the biggest things I've now learned from it is that one of the biggest things I found was that you become so reliant and so dependent on them that when you leave, you sort of sit at home and you're like, God, I really miss the place and I miss the people and I find it really hard to sort of come away” Harry: “they were just all so calm and so relaxed about it. You almost sort of wanted somebody to panic a bit to prove it was important.” Harry: “you’re there for Ward rounds and they're like, oh, chronic bone disease, chronic lung disease. There's, you know, it's a huge list of things you think, oh, my God. But what they don't say is because they can't, is we're probably going to fix all this. So don't worry about it.” Harry: “You know, I'm not thick and I don't want it to be covered in, you know, pretty colours. Tell me the facts. Tell me what you're thinking of doing about it” Harry: “I think that was one of the hardest things to cope with when we left is you, you developed a huge connection with all these people and then you didn't need them anymore” Harry: “the amount of overwhelming love you receive from all the staff and the support and everything else, just sort of it really made you feel cared for and it that offset all the bad bits completely”
3.2 An extended family	Aaron: “I suppose it made you feel more at ease, cause, they're sharing the same experience. Maybe not directly, but they're sharing the same kind of experience as you” Aaron: “But like the guy who'd had the triplets he'd been in there once when one of them had died. So obviously, that's horrific. And so you kind of just feel sorry for them and their parents.” Billy: “I remember there was a mum and dad in front of me and as soon as we got out, saw into the out of the building. The both of them burst into tears and that that wasn't really that uncommon to be honest.”

	Curtis: “a volunteer mother. Of. A child that had been through NNU and I thought that was a really invaluable, invaluable advocate to have to sort of say, do you know what, I might not be a medical professional, but I have complete empathy and an understanding” Curtis: “It was a real nice comfort to go. You know, you're not alone.” Curtis: “it is just a family. It's an, it's an extension of your family because you're not able to look after your parents, your, your, your children. But. And trust other people that become very dear to you to do so.” Curtis: “there's a lot of people that you see and start up conversations with because you're all in. Similar circumstances and you share thoughts and emotions and and they've become part of your journey as well.” Darren: “Because I remember them. Because there was really old lady stood over them crying. I remember then there were a couple others” Darren: “The feeling I got was they look really sick, like they're going to die. Is that going to happen to, *****?” Darren: “I think being in that environment, you just kind of make that, I made that perception that that was going to happen. And so that was one of the reasons I didn't. I didn't leave.” Edward: “was kind of nice to be able to, like, like, have a little chat and just say, you know, don't don't, don't sweat it. We all make mistakes and it's, you know, maybe it'll be fine.” Edward: “Yeah, it kind of like there was a little bit of a family atmosphere to some extent, depending on personalities of the parents.” Edward: “You know, I was probably walking around like a spaceman. You know, I didn't kind of have that time to think or to form relationships”

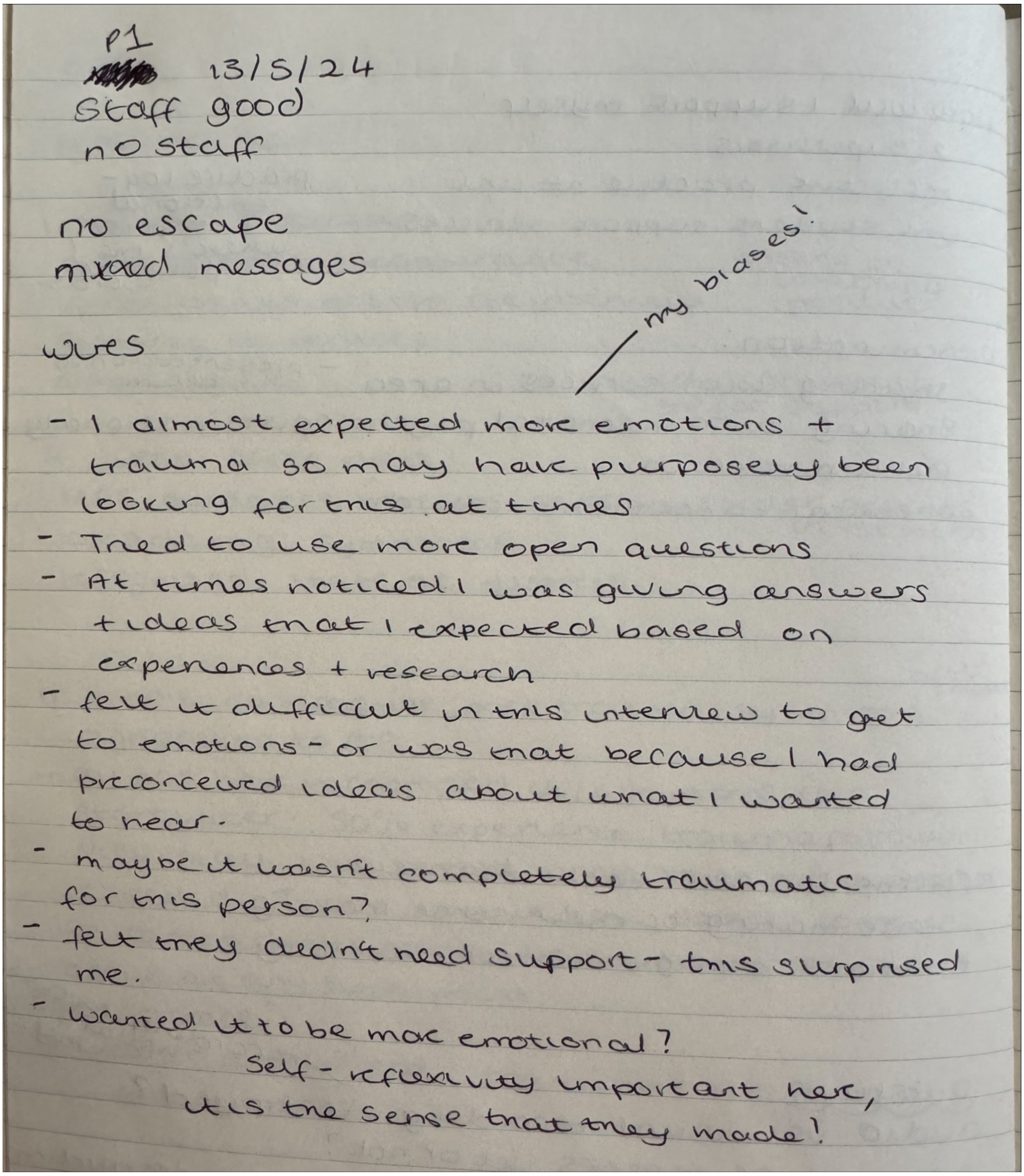
	Edward: “it gives you a bit more insight into what other people are going through. A bit of empathy” Edward: “I think in a lot of ways, a lot of the things people think, oh, yeah, you've got a child who's been on NICU. That's the only child you've got.” Freddie: “you got a little bit of guilt there when you look around at other parents when you look around at other parents who kind of aren't able to like hold their kid” Freddie: “it's just not what's happening to your kid is is what's happening to everybody else around as well that I think plays a big factor” Freddie: “you've got to deal with all the harrowing stuff that goes on around whether it's your kid or or kind of it or what's going on to other peoples as well” Freddie: “I almost it's kind of personal. I'm not kind of fill it upon myself to like, go and speak to everybody new.” Feddie: “I did always like kind of try and take two minutes just to like like I say hello and go anything you want to talk about” Gavin: “one of the twins had passed away, which which, you know, really affected me so much as I’m a twin, as well” Gavin: “you know, literally one of them, you know, literally died while we're in the room type thing.” Gavin: “if you see something happen or you hear something happen, you know you hear bad news. You then start projecting that onto your own situation. You think? Well, ****, if that happens to this person, can it happen to us?” Gavin: “We tried to just, I don't know, help them as much as we could, but we couldn't really do anything, obviously”

	Gavin: “I've no interest in anybody apart from the staff and my child and wife because I was. Yeah, I was so selfish. But that's that's what I had to. I had to deal with that.” Gavin: “Don't care. I haven't got enough space in my own brain for my own situation. I don't want to care about anybody else's” Harry: “there are other families in there that think it's the end and you almost sort of want to go in with the banner and go. Don't panic. It's brilliant in here. But you can't because people are obviously, you know, they're stressed, they're upset, they're struggling” Harry: “it sort of became a thing where once everything had settled down, it'd be like, come on, I'll show you around the unit. I'll show you where everything is” Harry: “I think another thing that we were quite fortunate with that helped us a lot was that there was another couple in the like the bay next to us” Harry: “I mean and I think that was one of the big things that really helped us through it all was that feeling of family. “ Harry: “it was such a lovely feeling of family”
3.3 To talk or not to talk?	Aaron: “I messaged my mates a few times. You know, if it it stressed me out or I'd got too wound up by it. They just do the usual. Just talk. Talk to you a little bit and as soon as you've got it off your chest, you feel better already anyway.” Billy: “The amount of attention, especially as sick premature child needs, I don't really think I'd, I'd be talking to anybody else, and I don't really think I'd be. I don’t have a care in the world about what anyone else has to say, to be honest.” Curtis: “everything happened so quickly that I don't feel you have the means to be able to. To stop in that moment and. Critically, reflect back on what did it feel like? How did I feel?”

	Curtis: “there isn't a right emotion for what you're going through. I think you can put. An awful lot on your shoulders in that sense of blame or guilt or. But you know it's OK, it's. It's important to keep talking” Curtis: “that is a double edged sword because one I think you have. A need for it, potentially. I think there's always nice to have the opportunity but to turn it down rather than not be offered something” Curtis: “That is is really helpful because you get sort of a medical professional's ability to, yeah, to rationalise and like I said, compartmentalise your thinking.” Curtis: “Could I have taken advantage of it more? Yes, 100 percent, 100%. Did I choose not to for my own. Sense of. Protecting myself from feeling vulnerable, yes.” Edward: “I think that's kind of good as a dad because you can decide whether you want to engage with it or not.” Edward: “And I think it's good not to have something forced down your throat. Really because. At the time you, you're dealing with a lot. And you're probably not in the best place, but it's nice to have the information that you know if you needed something later.” Edward: “For men to talk, it takes a lot of guts, I think sometimes. You know, it's not. It's not a neutral move for them to talk because we were talking about” Freddie: “The thing is, some people just don't want to talk and that's fair. You kind of not got to take that to heart. Everyone handles things differently” Freddie: “Do you spend your time with your kid or do you? Or do you go in and have that session of talking to someone?”

	Freddie: “that was one of the things that kind of struck me massively is that I get that it's there, but it's there, but I don't think it's it's as accessible as as needs to be.” Freddie: “But they're all they're always on hand. There's like someone to talk to someone to talk to as well.” Freddie: “part of it is the the inaccessibility of the thing and the part of it is actually who's, who's available to talk to.” Freddie: “it always felt like a very formal thing because it was like, OK, right we’re counsellors were here like come and book at like common booking at common booking a session. And I think that can almost almost like. Put guys up, put guys off at times as well, like like I don't need this” Freddie: “I think the option to have like a panel of dads that have been through this. I don't think anything else. I think for me personally that would probably be the best thing.” Gavin: “just to have somebody to ring up and talk to” Gavin: “I'm not one first sort of random small talk. Because I've got my own things to worry about, frankly” Harry: ”the more you talked about it, the better it was. And it's like the first time you told it, you could hardly get through it. And by the end of it, you were sort of like, oh, yeah, no, that was brilliant” Harry: “I don't think there's anything anybody could do about it, but certainly talking about it's helped a lot. I'll I would advise anybody who stays in the nicu for more than a couple of weeks to talk to somebody about it” Harry: “It was nice to just share them feelings and like even doing stuff like this, I just enjoy talking about my experience”

Appendix L- Excerpts from researchers' reflective diary



P1

[redacted] 13/5/24

Staff good

no staff

no escape

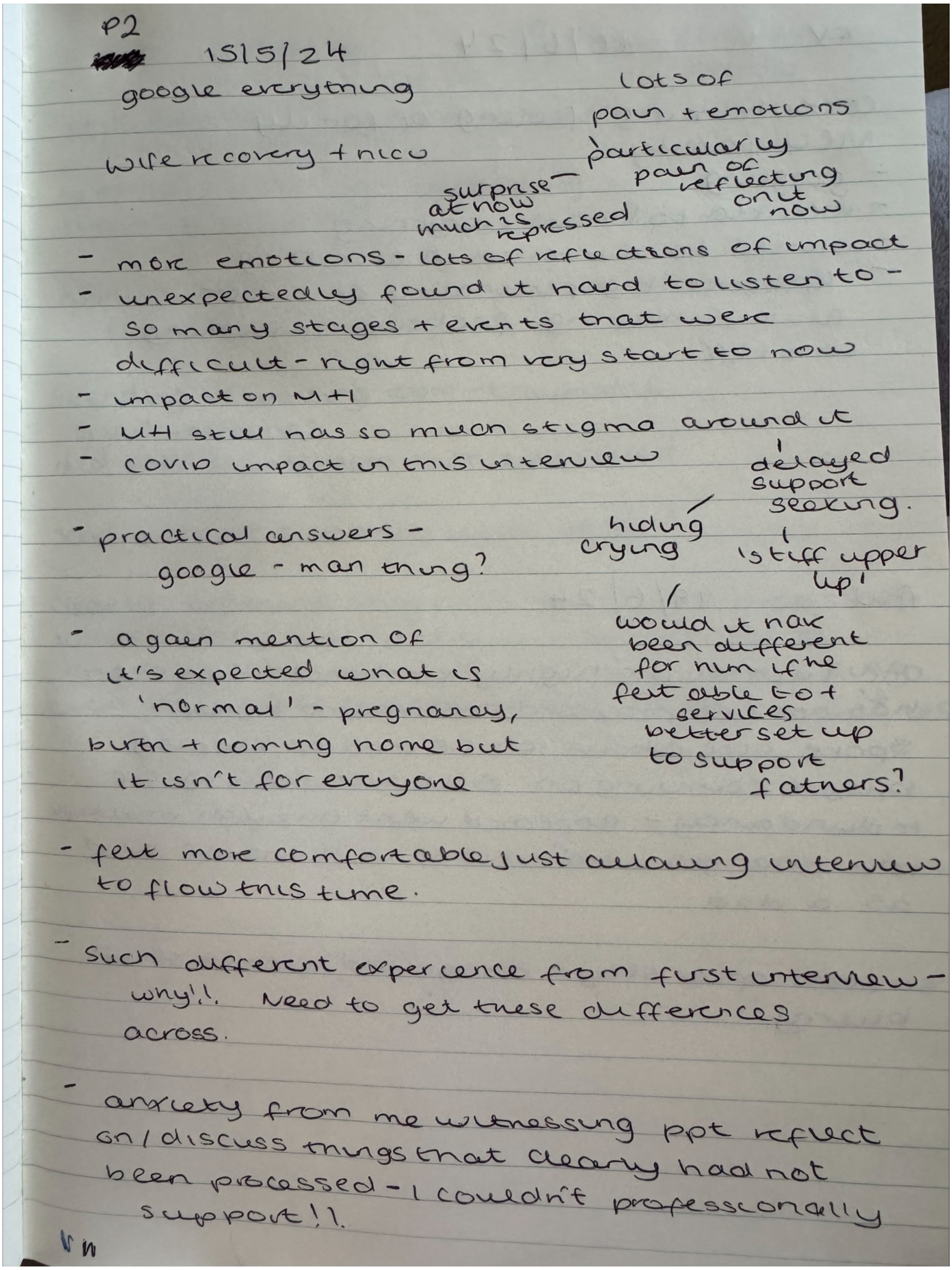
mixed messages

wires

my biases!

- I almost expected more emotions + trauma so may have purposely been looking for this at times
- Tried to use more open questions
- At times noticed I was giving answers + ideas that I expected based on experiences + research
- felt it difficult in this interview to get to emotions - or was that because I had preconceived ideas about what I wanted to hear.
- maybe it wasn't completely traumatic for this person?
- felt they didn't need support - this surprised me.
- wanted it to be more emotional?

Self - reflexivity important here, it is the sense that they made!



P2

[redacted] 15/5/24

google everything

lots of pain + emotions

particularly pain of reflecting on it now

wife recovery + nicu

surprise at how much is repressed

- more emotions - lots of reflections of impact
- unexpectedly found it hard to listen to - so many stages + events that were difficult - right from very start to now
- impact on MH
- MH still has so much stigma around it
- COVID impact in this interview

delayed support seeking.

hiding crying

'stiff upper lip'

- practical answers - google - man thing?

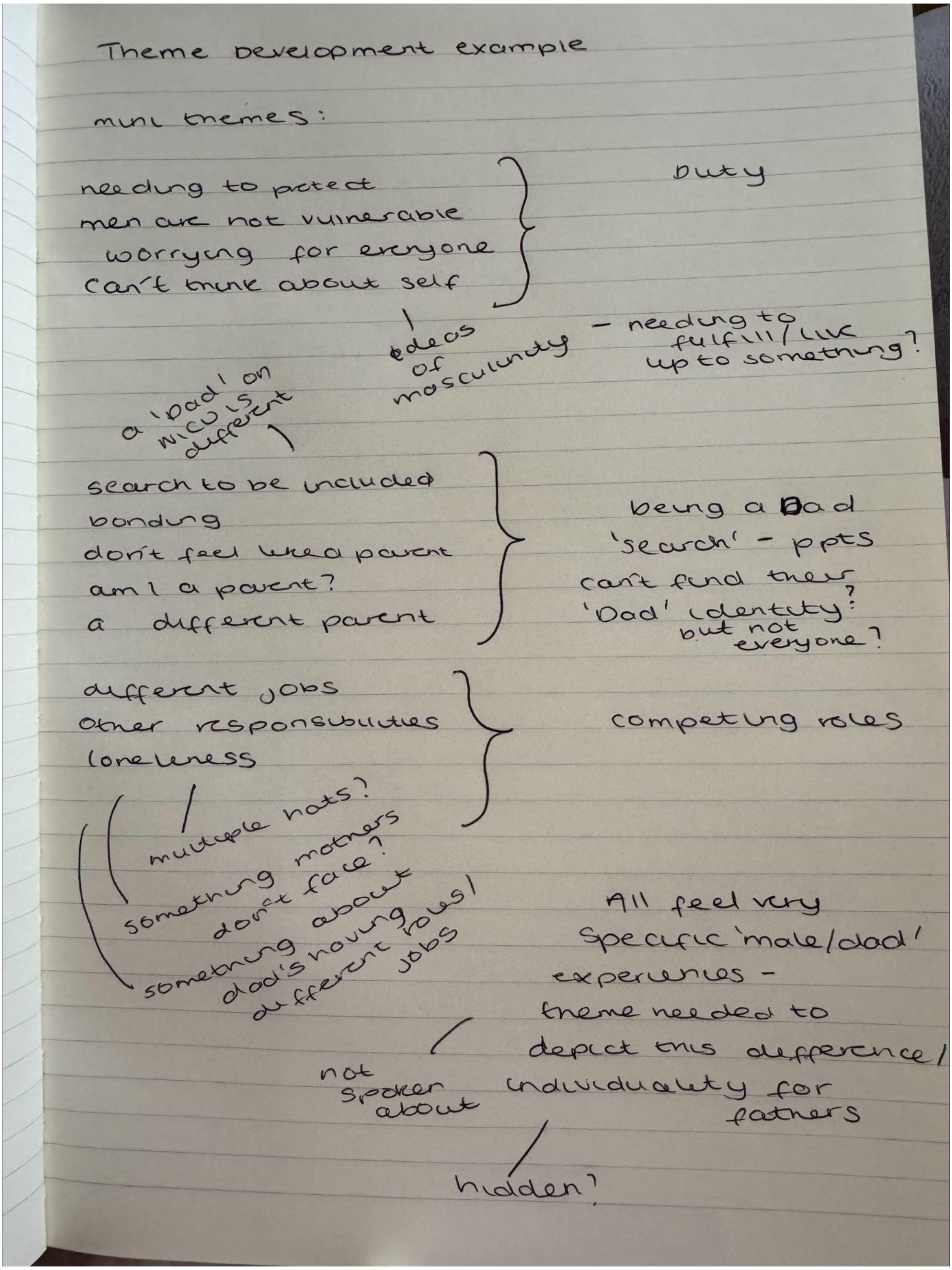
- again mention of it's expected what is 'normal' - pregnancy, birth + coming home but it isn't for everyone

would it have been different for him if he felt able to + services better set up to support fathers?

- felt more comfortable just allowing interview to flow this time.

- Such different experience from first interview - why!!. Need to get these differences across.

- anxiety from me witnessing ppt reflect on/discuss things that clearly had not been processed - I couldn't professionally support!!.



Theme Development example

mini themes:

needing to protect
men are not vulnerable
worrying for everyone
can't think about self

Duty

ideas of masculinity – needing to fulfill/live up to something?

a 'Dad' on NICU is different

search to be included
bonding
don't feel like a parent
am I a parent?
a different parent

being a Dad
'search' – ppts can't find their 'Dad' identity?
but not everyone?

different jobs
other responsibilities
loneliness

competing roles

multiple hats?

something mothers don't face?

something about dad's having roles/ different jobs

All feel very specific 'male/dad' experiences – theme needed to depict this difference/ individuality for fathers

not spoken about

hidden?

Appendix M- Publication guidelines for targeted journal: Qualitative Health Research

3. Preparing your manuscript for submission

We strongly encourage all authors to review previously published articles in *QHR* for style prior to submission.

QHR journal practices include double anonymization. All identifying information MUST be removed completely from the Abstract, Manuscript, Acknowledgements, Tables, and Figure files prior to submission. ONLY the Title Page and Cover Letter may contain identifying information. See Sage’s general submission guidelines for additional guidance on making an anonymous submission.

Preferred formats for the text and tables of your manuscript are Word DOC or PDF. The text must be double-spaced throughout with standard 1-inch margins (APA formatting). Text should be standard font (i.e., Times New Roman) 12-point.

3.1 Title page

- The title page should be uploaded as a separate document containing the following information: Author names; Affiliations; Author contact information; Contribution list; Acknowledgements; Ethical statement; Funding Statement; Conflict of Interest Statements; and, Grant Number. Please know that the Title Page is NOT included in the materials sent out for Peer Review.
- Ethical statement: An ethical statement must include the following: the full name of the ethical board that approved your study; the approval number given by the ethical board; and, confirmation that all your participants gave informed consent. Authors are also required to state in the methods section whether participants provided informed consent, whether the consent was written or verbal, and how it was obtained and by whom. For example: “Our study was approved by The Mercy Health Research Ethics Committee (approval no. XYZ123). All participants provided written informed consent prior to enrollment in the study.” If your study did not need ethical approval (often manuscripts in the Pearls, Piths, and Provocations may not), we still need a statement that states that your study did not need approval and an explanation as to why. For example: “Ethical Statement: Our study did not require an ethical board approval because it did not directly involve humans or animals.”

3.2 Abstract and Keywords

- The Abstract should be unstructured, written in narrative form. Maximum of 250 words. This should be on its own page, appearing as the first page of the Main Manuscript file.
- The keywords should be included beneath the abstract on the Main Manuscript file.

3.3 Manuscript

- Length: 8,000 words or less excluding the abstract, list of references, and acknowledgements. This applies to both Original Research and Pearls, Piths, and Provocations. Please note that text from Tables and Figures is included in the word count limits. On-line supplementary materials are not included in the word limit.
- Structure: While many authors will choose to use headings of Background, Methods, Results, and Discussion to organize their manuscript, it is up to authors to choose the most appropriate terms and structure for their submission. It is the expectation that manuscripts contain detailed reflections on methodological considerations.
- Ethics: In studies where data collection or other methods present ethical challenges, the authors should explicate how such issues were navigated including how consent was gained and by whom. An anonymized version of the ethical statement should be included in the manuscript (in addition to appearing on the title page).
- Participant identification: Generally, included demographic features or other participant information should be described in narrative form or otherwise reported in aggregate form as a group with limited specific and individual identifiers. Quotations may be linked to particular participants and/or demographic features provided measures are taken to ensure anonymity of participants (e.g., use of pseudonyms). Including such information should clearly connect to the purpose and analysis of the research. In other words, if individual details are included, this should be clearly related to the qualitative analysis
- Use of checklists: Authors should not include qualitative research checklists, such as COREQ (COnsolidated criteria for REporting Qualitative research). Generally, authors should use a narrative approach to describe the processes used to enhance the rigor of their study. For additional information on this policy, please read Why the *Qualitative Health Research* (QHR) Review Process Does Not Use Checklists
- References: APA format. While there is no limit to the number of references, authors are recommended to use pertinent references only, including literature previously published in *QHR*. References should be on

a separate page. *QHR* adheres to the APA 7 reference style. View the APA guidelines to ensure your manuscript conforms to this reference style. Please ensure you check carefully that both your in-text references and list of references are in the correct format.

- Authors are required to disclose the use of generative Artificial Intelligence (such as ChatGPT) and other technologies (such as NVivo, ATLAS. Ti, Quirkos, etc.), whether used to conceive ideas, develop study design, generate data, assist in analysis, present study findings, or other activities formative of qualitative research. We suggest authors provide both a description of the technology, when it was accessed, and how it was used (see https://uk.sagepub.com/en-gb/eur/chatgpt-and-generative-ai).
- Manuscripts that receive favorable reviews will not be accepted until any formatting and copy-editing required has been done.

3.4 Tables, Figures, Artwork, and other graphics

- Tables should be used sparingly and mindfully to augment what is written in the manuscript. Do not use tables to simply list demographic information about participants as too many individual details may compromise the confidentiality of participants.
- In general, identifying features should not be contained within images. For example, in photographs faces should generally be concealed using mosaic patches – unless permission has been given by the individual to use their identity. This permission must be included at the time of submission.
    1. TIFF, JPED, or common picture formats accepted. The preferred format for graphs and line art is EPS.
    2. Resolution: Rasterized based files (i.e. with .tiff or .jpeg extension) require a resolution of at least 300 dpi (dots per inch). Line art should be supplied with a minimum resolution of 800 dpi.
    3. Dimension: Check that the artworks supplied match or exceed the dimensions of the journal. Images cannot be scaled up after origination.
- Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in color in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from Sage after receipt of your accepted article.

3.5 Supplemental material

- **Core elements of the manuscript should not be included as supplementary material.**
- ***QHR*** is able to host additional materials online (e.g., datasets, podcasts, videos, images etc.) alongside the full-text of the article. For more information please refer to Sage's general guidelines on submitting supplemental files.

Paper Three: Executive Summary

"It's a place I will never forget"

Fathers' Experiences of Neonatal Care: An Interpretative Phenomenological Analysis Study

Word Count: 2093

(Excluding title page and references)

Target audience: Who is this summary written for?

- Parents and families of the Neonatal Care Community
- Professionals working within Neonatal Care wanting to understand more about the psychological experiences of fathers during their NICU journey
- Members of the public that wish to understand about fathers' experiences of neonatal care and what it is like for parents on NICUs.

Fathers were consulted on the design of this research, particularly in the design of the poster advertising the study and the questions asked during the interview. Many thanks are extended to all the fathers who supported this project.

Background to the research: Why was it important to complete this research?

An infant may require a stay on a NICU for several reasons such as prematurity, or ill-health at full term. Having an infant on a NICU is an often difficult and challenging time for parents. Research has evidenced both mothers and fathers face stress, anxiety and low mood throughout their journey on the NICU (Shaw et al., 2009). However, little is known about how fathers experience their journey through neonatal care with their families. Fathers have different roles as a parent and on the NICU, such as often being the first parent to see their newborn infant on the NICU if their partner is unwell or recovering, with many having to go work, look after the house and other children whilst negotiating a stay on a NICU (Merritt et al., 2021). These differences may mean fathers have different experiences on the NICU. These differences should be understood so fathers can be supported effectively throughout their journey with their infant in neonatal care. It is important to understand fathers' stories as fathers' poor mental health can cause poor outcomes in children (McManus & Poehlmann, 2012) and can affect their personal relationships and marriages (Bernardo et al., 2021). Gaining a better understanding of what fathers' experience in neonatal care will help to improve the support offered to fathers.

Aim: What did this research hope to do?

To understand the experiences of fathers in neonatal care in England

Method: What we did

Step 1: The research proposal was reviewed by the University Ethics Committee who stated the study was ethical and could go ahead

Step 2: A poster advertising the study was placed in an NHS Hospital, on social media platforms e.g. Instagram and emailed to psychologists working within neonatal care in England to share within their teams.

Step 3: Fathers who wanted to take part, emailed the researcher themselves and then read an information sheet and signed a consent form.

Step 4: The researcher and father agreed a time to meet. Interviews were recorded over video call. Eight fathers took part in the study.

Step 5: Interviews were analysed by the researcher using a method called 'Interpretative Phenomenological Analysis'. This is one type of analysis that is useful for understanding people's stories in detail. The researcher spent time understanding what each participant said and the meaning behind what they said. From this, the researcher was able to find themes in what each participant said and themes across all participants.

Results: What we found

Three main themes were found, with nine smaller sub-themes included.

The emotional rollercoaster:

A thunderstorm of emotions

Many participants spoke about feeling out of control and bewildered in neonatal care, not knowing what was happening to them or their families, not knowing what was going on around them or what might happen next. This led to fathers feeling they were in an ‘emotional rollercoaster’ and a whirlwind’, filled full of uncertainty and unknown. For some this made it hard for them to process what was happening to them whilst on the unit however others felt the experience shouldn’t be assumed to be traumatic, with one father feeling able to understand better what was going on. All fathers spoke about the many ups and downs on the unit and how quickly things can change from positive to negative and vice versa.

“You feel like you have to rush back and just in case they aren’t alive when you when you come back.” (Billy).

“Just such a rollercoaster. Some days you could go in and you'd be dead happy. And then the next minute, something had happened” (Harry)

The NICU experience lives on

For many fathers their NICU experience stayed with them, with some describing how they still worry about the infants and partners after leaving the NICU, such as worrying about their infant being ill again or their partner in future pregnancies. Some fathers explained how for them, the emotional impact related to their stay on the NICU was not felt for some time after they had left the NICU, showing that sometimes fathers aren't able to process their feelings at the time, but this comes later. With other fathers speaking about how they will never forget their NICU experience and feel affected by it a time after their stay.

"Convinced they were going to kill my wife by accident, or she was going to die and I think… I was just so overwhelmed with anxiety that it was going to happen again" (Darren)

"There's definitely some underlying, you know, whether you want to call it PTSD or whatever it definitely affected me. And I think it's going to take a long time for it to, you know, dissipate off." (Harry)

Grief is multi-faceted: from loss to growth

This theme showed how there are many different types of loss, fathers are grieving on the unit. Some that are forgotten about, such as, getting a photo of the father carrying their baby out in their car seat, to having newborn photo shoots and to family meeting the infant for the first time at home. Grief is complex on the NICU for fathers. But some fathers spoke about how they became better people in their relationships and being a better parent.

“Think one thing I've skimmed over is the impact of coming home without them. I think that was one of the worst experiences I've ever had… we got home and they (family) decorated the house, and it was a really big reminder that they weren't here.” (Billy)

“it is massive and that has helped for me and my wife. You know, we've shown we can work as a proper team which you need to as your parents. So that's made us sort of more, stronger as a couple as well I think.” (Gavin)

The hidden not heard experience:

My duty as man

Some fathers reflected that it was important to them to remain strong in-front of their partner to not add further worry or stress into their situation. Some fathers also felt they had no choice but to power through their journey and just try to keep going even when things became difficult, possibly due to fathers’ expectations on themselves as a man to appear strong and positive regardless of what they are going through.

“I didn't get upset because I think my roles are this, like, subconsciously was to reassure my wife and to make her feel like everything was going to be OK” (Billy)

“I just kind of took it in my stride and kind of had to. I think that's the key thing really. Kinda not really got any other choice.” (Freddie)

The strain of competing roles

This theme spoke to the wider responsibility's fathers have whilst on the NICU, including balancing working with looking after the home and other children, whilst caring for their infant and partner. Some fathers spoke about the overwhelming worry they experience about their partner, so not only do fathers have their infant to worry about but also their partner, especially following traumatic births, leaving some fathers feeling torn between whether they should be with their infant or their partner which was difficult for fathers. This theme highlighted some of the father specific pressures on the NICU.

> "But by the time I've gone to work. Go and see him doing the dogs, blah, blah, blah. Then you'd be physically tired. You know what I mean? So, it was like you was getting drained from both mental and physical." (Aaron).
>
> "Where you're supposed to be, you're supposed to be like with the baby. You're supposed to be with your wife like that. I think that's probably the most difficult thing." (Freddie).

The unique experience of a NICU dad

Being a parent on the NICU is different from the traditional sense, participants spoke about their frustration at times of how little space they had to feel like a normal dad on the unit, doing things such as feeding and touching their infant. Some did not feel they could identify as a dad initially on the unit. However, others, when looking back on their journey, spoke about how having their infant on the NICU, gave them more time to bond with their infant, just them together.

“not at any point would I have identified that I had the little ones, I was in their company in a room where I was not really able to get anywhere near them. You can't touch them. You can't parent them.” (Curtis).

“he kind of has like a little bit more connection with me and is that because, you know, in the first few days of his life, he saw more of me than he did his mum.” (Edward).

The people around you: help or hinder?:

Staff make a difference

Whilst on the unit, families are constantly supported by staff, some fathers described this as a positive, with the staff giving them a ‘psychological boost’ when they needed it by reminding parents of the positives of their journey and at times, how well their infant was doing. However, at other times, relationships with staff made the experience more difficult, with some fathers feeling they were not communicated with about what was happening to their infant and some staff not showing the empathy and understanding the fathers needed.

“the amount of overwhelming love you receive from all the staff and the support and everything else, just sort of it really made you feel cared for and it that offset all the bad bits completely” (Harry)

“One day we got there, and we walked into where he was the night before and his incubator was empty. So, I instantly like what's going on here. Has he died? Which first thing that's popped in your head, but all that happened is they moved him and not told us.” (Aaron).

An extended family

Many participants spoke about the feeling of family and camaraderie between families on the NICU and how this helped them to feel like they were not the only ones going through it. Although, a father with other children felt at times he did not have the same experience as other families as he could not spend all his time on the NICU, so this led to him feeling separate at times to other families. Some fathers did find it hard to be surrounded by other families due to the harrowing sights and sounds of other poorly infants.

“I mean and I think that was one of the big things that really helped us through it all was that feeling of family.” (Harry).

“if you see something happen or you hear something happen, you know you hear bad news. You then start projecting that onto your own situation. You think? Well, ****, if that happens to this person, can it happen to us?” (Gavin)

To talk or not to talk?

Lastly, fathers spoke about at times finding it difficult to talk about their experiences to professionals and at times simply just not wanting to have support for their experiences, some found seeing a professional intimidating and wanted to see more men offering support. Some spoke about knowing the benefits of talking and had found it helped to speak to mates and other dads who understand their stories in a more informal way of chatting about and processing their feelings.

“I messaged my mates a few times…Talk to you a little bit and as soon as you've got it off your chest, you feel better already anyway.” (Aaron)

“part of it is the inaccessibility of the thing and the part of it is actually who's, who's available to talk to….I think the option to have like a panel of dads that have been through this” (Freddie).

Conclusions and recommendations: What does this mean?

This study showed some of the experiences of fathers who have had an infant stay in neonatal care in England. Fathers spoke about a range of difficult experiences such as the up and down emotional turmoil on the unit, to a longing to feel like a dad and conflict about whether to access support or not and who to turn to for support. These difficulties suggest as previous research has, that fathers face a range of difficulties and stresses throughout their time in neonatal care. However, what this research does offer, is an insight into some of the positive experiences for fathers such as their bonding with other families and staff, to their close connections with their infants and how their journeys have made them better parents and have stronger relationships with their spouses. Whilst we know a NICU stay is tough; it is worthwhile acknowledging some of these ‘glimmers of light’ from participants stories.

Recommendations:

- Consider support for fathers on a case-by-case basis- not all fathers need or want formal talking therapy
- Offer creative ways of support such as coffee catch- ups with fellow fathers
- Employing males to offer professional support on NICUs
- Consider post-NICU support for fathers
- Include fathers in the care of their infant as much as is medically possible
- Some fathers may not understand their feelings about their journey- need for validation and space to process their experiences

Dissemination: How will this research be shared?

The full research report will be submitted for publication in a peer-reviewed journal. The ‘executive summary’ will be shared with participants who requested it and professionals working within neonatal care.

References

Bernardo et al, 2021. ‘Parental Stress and Mental Health Symptoms in the NICU: Recognition and Interventions’. *Neoreviews (2021) 22* (8): e496–e505.

McManus, B. M., & Poehlmann, J. (2012). Parent-child interaction, maternal depressive symptoms and preterm infant cognitive function. *Infant behavior & development*, *35*(3), 489–498. https://doi.org/10.1016/j.infbeh.2012.04.005

Merritt L. (2021). An Integrative Review of Fathers' Needs in the Neonatal Intensive Care Unit. *The Journal of perinatal & neonatal nursing*, *35*(1), 79–91. https://doi.org/10.1097/JPN.0000000000000541

Shaw, R. J., Bernard, R. S., Deblois, T., Ikuta, L. M., Ginzburg, K., & Koopman, C. (2009). The relationship between acute stress disorder and posttraumatic stress disorder in the neonatal intensive care unit. *Psychosomatics*, *50*(2), 131–137. https://doi.org/10.1176/appi.psy.50.2.131