University of Glasgow

Gilmour, Rachel (2023) *Exploring the assessment of parental stress within the neonatal environment.* D Clin Psy thesis.

https://theses.gla.ac.uk/83869/

Copyright and moral rights for this work are retained by the author

A copy can be downloaded for personal non-commercial research or study, without prior permission or charge

This work cannot be reproduced or quoted extensively from without first obtaining permission from the author

The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the author

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given

Enlighten: Theses
https://theses.gla.ac.uk/
research-enlighten@glasgow.ac.uk

Exploring the assessment of parental stress within the neonatal environment

Rachel Gilmour MA (Hons.)

Submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology

School of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

September 2023

Contents

List of Tables

List of Figures

Acknowledgements

Chapter 1 8

Caregivers' experience of having an infant in the Neonatal Intensive Care Unit: A systematic review

Abstract 9

Introduction 10

Previous systematic reviews 10

Purpose of current systematic review 11

Methods 11

Protocol and Registration 11

Search Strategy and Sources 11

Search Terms and Eligibility Criteria 12

Screening 13

Critical Appraisal 13

Data Synthesis 13

Results 14

Study characteristics 16

Quality appraisal 23

Synthesis 23

What are parents' experiences of having an infant in the NICU? 25

The physical environment 25

Financial concerns 26

Heightened emotions in the NICU environment 27

Separation from baby 29

Discharge home 29

Experiences specific to fathers 30

What has been helpful/unhelpful for parents 30

Discussion 33
Review limitation and risk of bias 35
Review Strengths 36
Future recommendations and conclusions. 37
References 38
Chapter 2 41
Exploring the assessment of parental stress within the neonatal environment: A qualitative study of Psychologists'' views
Plain language summary 42
Abstract 44
Introduction 45
Stress 45
Becoming a parent in the Neonatal Intensive Care Unit (NICU) 46
The role of psychology in the NICU 46
Measuring parental stress in the NICU 47
Current clinical context 48
Aims 49
Research Questions 49
Methods 49
Design 49
Ethical approval 49
Participants 50
Recruitment 50
Materials 50
Procedure 51
Data Analysis 51
Sample size 52
Reflexivity 53
Results 54
Participant characteristics 54
Development of the framework 54

Current practice 55
Existing tools 57
Is it needed? 61
Discussion 63
How are NICU psychologists currently assessing parental stress in the neonatal environment? 63
What are NICU psychologists' experiences of using standardised measures for this purpose and what are their views on the strengths and limitations of those measures? . 64
What factors do NICU psychologists think would be useful to include in an ideal measure examining parental stress in the neonatal environment? 65
Strengths and limitations 66
Clinical Implication. 67
Conclusion 67
References 68
Appendix 1.1 70
Appendix 1.2 72
Appendix 1.3 76
Appendix 1.4 78
Appendix 1.5 84
Appendix 1.6 96
Appendix 2.1 97
Appendix 2.2 100
Appendix 2.3 101
Appendix 2.4 102
Appendix 2.5 103
Appendix 2.6 104
Appendix 2.7 105
Appendix 2.8 106
Appendix 2.9 107
Appendix 2.10 108
Appendix 2.11 109
Appendix 2.12 111

List of Tables

Table 1.1 – Breakdown SPIDER terms used. 12
Table 1.2 - Characteristics of included studies 17

List of Figures

Figure 1.1 - PRISMA flow diagram (Page et al, 2021) 15
Figure 1.2 - Idea Webbing 24
Figure 2.1 - Phrases of Framework Analysis (Ritchie and Spencer, 2002) 52
Figure 2.2- Map of final framework used for analysis. 55

Acknowledgements

To Dr Breda Cullen, you have taught me so much and I am extremely thankful to have had you as my Academic Supervisor. Thank you for sharing your knowledge and holding my hand through this research journey. You have made this an enjoyable experience and thank you for sharing your passion for research with me.

To Dr Marisa Forte, thank you so much for your support during my three years of training, from my Local Area Tutor to Field Supervisor-with a placement thrown in- you have been with me every step of the way! You have nurtured, supported, and shaped my training journey and this process has undoubtedly been made easier with your support.

To Dr Katie Robb, thank you for guidance and support as my Research Advisor, it was a pleasure to work with you. To Dr Paul Cannon, thank you for your help in developing my search strategy and sharing your expertise and knowledge with me. To Emma Jayne Gault, thank you for your patience, support, and guidance in helping me navigate the ethics process for this project.

To the clinicians who participated, thank you all so much. Each one of you showed passion and love for what you do, and it was inspiring to hear! Thank you for taking the time to share your experiences with me, this project couldn't have happened without you.

To my friends, thanks to each and every one of you. Thank you for never complaining when I couldn't make plans, for always being at the end of the phone and for supporting me throughout this entire journey. I can't wait to spend more time with you all.

To my family, I don't think I would have made it to this point without your love and support. To Rob, thank you for proof reading everything I have ever written- you have always gone above and beyond to help me reach my dreams. To my mum, you taught me to chase my dreams and to reach for the stars. Thank you for being there through it all, I am very lucky to have you.

And finally, Max. Thank you for being my biggest cheerleader and for always believing in me! Thank you for supporting me every single step of the way and for all the small things (especially the ice cream), big things and everything in between that made this process easier. I love you to the moon and back.

Chapter 1

Caregivers' experience of having an infant in the Neonatal Intensive Care Unit: A systematic review

Prepared in accordance with the author requirements for Journal of Perinatology.

https://www.nature.com/jp/authors-and-referees/guide-to-authors

Abstract

An infant's admission to the Neonatal Intensive Care Unit (NICU) is a stressful and challenging time for parents, by understanding how parents experience the NICU, professionals are better equipped to understand how this may impact on the family. A previous systematic review by Al Maghaireh et al. (2016) explored parents' experience in NICU. In the years since that review, there have been advances in care and treatment within the NICU and a global pandemic (COVID-19). This current review aimed to expand on their findings, providing an updated synthesis and quality appraisal of the contemporary qualitative literature in this field. It also aimed to examine what has been helpful/unhelpful for families within this environment. Medline, EMBASE, Maternity and Infant Care (MIDIRS), PsycInfo, CINAHL and Web of Science were searched up to March 2023 for qualitative studies exploring parents' experience of the NICU. 18 studies were included in the narrative synthesis. The quality of each study was critically appraised using the CASP checklist. Analysis of included studies resulted in six themes: The physical environment, heightened emotions, separation from baby, discharge home, experiences specific to fathers and what has been helpful/unhelpful. Similar themes to the previous review were found however new themes were also discovered. The review presents the current evidence on how the NICU is experienced and what has been helpful/unhelpful for parents from their own perspective. Professionals need to be aware of the practical ramifications of having an infant in the NICU and provide support where available to parents. Also, countries where restricted access is still current practice, professionals need to consider how they can facilitate more 'hands-on' care for parents as technology was found to not be a substitution for actual physical contact. Same sex parents and other primary caregivers in NICU are under-researched populations.

Key words: Neonatal Intensive Care Unit; Parents; Caregivers; Qualitative research.

Introduction

Neonatal care provides new-born babies with the highly specialist care and treatment they require. Approximately one-in-seven babies require neonatal care because they are born prematurely (under 37 weeks' gestation), have too low a birth weight (increasing their risk of developmental delay) or have a medical condition requiring specialist treatment (Royal College of Paediatrics and Child Health (RCPCH), 2022). The Neonatal Intensive Care Unit (NICU) specialises in providing care and treatment for the sickest babies.

As a major developmental transition, parenthood can be challenging. Parents may hold specific expectations about it and an admission to the NICU is often at odds with those expectations (Loewenstein et al., 2019). The experience of having an infant in the NICU is usually unexpected and is a significant source of stress (Miles et al., 2002). Parents may be unprepared for the hospitalisation of their infant and subsequent outcomes, threatening their psychological wellbeing and making this transition more difficult to navigate (Affleck and Tennen, 1991).

Family Centred Care (FCC), used widely within the NICU, is a model of health care which recognises the significant role family members play in the well-being of hospitalised infants (Finlayson et al., 2014). It is grounded in a mutually beneficial partnership between professionals and parents and seeks to encourage parents to take a central role in their infant's care (Kutahyalioglu and Scafide, 2022), thus, improving parents' confidence and infant-parent bonding and creating a family-friendly environment.

Understanding the experience of parents with infants admitted to NICU, enables professionals to better understand how these experiences may impact on the family, their experience, and the delivery of FCC.

Previous systematic reviews

Previous systematic reviews of the NICU experience have focused on mothers' and fathers' experiences separately (Provenzi and Santoro, 2015, Wang et al., 2021). Mothers were found to have negative experiences in relation to the condition of their infant and the NICU environment and as a result experience negative emotions in NICU. However, mothers were able to form loving relationships with their infant if appropriate support was provided (Wang et al., 2021). Fathers experienced a range of emotions during their time in the NICU, however appeared to hide these as a way of coping within this environment. Their transition to the role of fatherhood appeared to progress during their infant's NICU stay (Provenzi and Santoro, 2015). Other reviews have focused more on the needs and stressors of parents in the NICU (Govindaswamy et al., 2019, Adama et al., 2022) rather than the overall NICU experience, recognising the importance

of information, emotionally intelligent professionals and tailored support for helping families navigate this environment.

Another systematic review which specifically focused on parents' experiences in the NICU (Al Maghaireh et al., 2016), highlighted three key themes: the stress of hospitalisation; the alteration in parenting roles and responsibilities; and the impact of infant hospitalisation on psychological and emotional health, with parents of pre-term infants reporting more psychological distress and emotional problems than parents of healthy full-term infants. This review included qualitative studies between 2004-2014.

Purpose of current systematic review

The current systematic review aimed to expand on Al Maghaireh et al. (2016) findings and conduct an updated synthesis and quality appraisal of contemporary qualitative literature within this field. In the years since that review there have been advances in care and treatment within NICU and a global pandemic (COVID-19) which undoubtedly contributed to parents' experiences. This review aimed to systematically examine parents'/caregivers' experience of the NICU.

Although there have been systematic reviews conducted looking at support needs within NICU (Govindaswamy et al., 2019, Adama et al., 2022), the current review took a broader approach, examining the entire experience of the NICU, which may highlight different themes not directly related to parents' support needs but are nevertheless of importance. Additionally, this review planned to expand the concept of 'parent' and include literature focusing on the wider primary caregiver (e.g., grandparents, adoptive parents) often overlooked in neonatal literature.

Methods

Protocol and Registration

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidance (Page et al., 2021) (Appendix 1.1, p70) was followed for this review. A protocol for this review was also registered on PROSPERO International Prospective Register of Systematic Reviews (CRD42023399247).

Search Strategy and Sources

The following electronic databases were searched on 1st and 2nd of March 2023: Medline (via Ovid), EMBASE (via Ovid), Maternity and Infant Care (MIDIRS) (Via Ovid), PsycInfo (via EBSCOhost), CINAHL (via EBSCOhost) and Web of Science (Core Collection). A backward and forward citation search of the reference lists of each of the final included studies was also conducted using Web of Science on May 12th, 2023, to locate any relevant papers.

Search Terms and Eligibility Criteria

The search terms were constructed using the SPIDER tool; see Table 1.1. This approach was adopted as the PICO model includes elements which are irrelevant or require manipulation for the qualitative paradigm (Cooke et al., 2012).

Table 1.1 – Breakdown SPIDER terms used.

Sample	Parents or Caregivers.
Phenomenon of Interest	Neonatal Intensive Care Unit.
Design	Qualitative data collection methods including semi-structured interviews, focus groups and field work.
Evaluation	Experience or Perception of the NICU environment.
Research Type	Qualitative studies of any type.

The search terms and database selection were devised in consultation with a specialist librarian. Three key components were identified: 'Neonatal Intensive Care Unit', 'Parents and Caregivers' and 'Qualitative research'. Searches were limited to the English language and the years 2014-present. The terms were adapted according to each database. See Appendix 1.2 (p72) for a detailed search strategy.

Studies were screened according to the following criteria.

Inclusion

- Qualitative studies only.
- Parents or caregivers with an infant in the NICU.
- Current or previous experience or perception of being in the NICU.
- English language.
- Peer-reviewed journal.
- Time span: 1st January 2014-3rd March 2023.

Exclusion

- Quantitative studies or mixed methods.
- Experience unrelated to the NICU environment and infant's admission.
- Experience focused on a specific intervention/experience (e.g., feeding, kangaroo care).
- Patents/caregivers who had lost an infant when in NICU or where there was a poor prognosis or end-of-life care was provided.
- Participants were health care professionals.
- Review articles, books, book chapters and conference papers/posters.

Screening

Duplicates were removed using EndNote software. The titles and abstracts of the remaining articles were screened by the primary researcher using a screening tool (Appendix 1.3, p76) developed to identify potentially relevant studies against inclusion/exclusion criteria. The full text of potentially relevant papers were then screened to determine eligibility.

A second reviewer screened a proportion (*n*=100) of titles and abstracts; agreement between raters was 98% (Cohen's *k*=0.83). A proportion (*n*=10) of full texts were also reviewed and agreement was 83% (Cohen's *k*=0.65). Any discrepancies were resolved through discussion.

Critical Appraisal

The quality of the included studies was assessed using the Critical Appraisal Skills Programme (CASP) tool (Critical Appraisal Skills Programme, 2022), which is a validated 10-item checklist (Appendix 1.4, p78).This was selected as it is considered to be user-friendly for novice qualitative researchers and is endorsed by Cochrane and the World Health Organisation (WHO) for use in qualitative evidence synthesis (Long et al., 2020) as it contains the key domains for consideration when assessing rigour in qualitative studies (Noyes et al., 2018).

A quality assessment of each paper was conducted by the primary reviewer. A proportion (*n*=5) of studies was randomly selected and reviewed by the second reviewer independently to ensure reliability. Agreement between raters was 90% (Cohen's *k*=0.81). No studies were excluded from the final review based on the critical appraisal as it was agreed that these studies could still make a valuable contribution to the synthesis. All quality issues will be discussed throughout the synthesis of the results.

Data Synthesis

A narrative synthesis was deemed the most appropriate approach to address the aims of the systematic review, as it systematically and transparently collates research findings and provides an overview of the existing knowledge whilst developing new insight (Pope et al., 2007).

The synthesis adhered to Popay et al. (2006) guidelines for narrative synthesis, which involved developing a preliminary synthesis of the data before exploring relationships within and between studies, followed by assessing the robustness of the synthesis.

Data extraction was conducted manually, with a tool designed by the lead researcher. The second reviewer also performed data extraction independently on a proportion (*n*=5) of the included studies to ensure reliability.

The material was synthesised by reading each paper and interpreting the key themes. This took an integrative approach, examining and summarising the data where the themes were already

well defined. The study characteristics were used to understand the relationships between the studies in line with the research questions of this review.

Results

A total of 7598 studies were identified through database searches. Following removal of duplicates, 3153 articles remained. The titles and abstracts were screened for the remaining articles, resulting in 31 papers being read in full and compared against the inclusion criteria, with 16 studies identified for inclusion. A further five papers were acquired during the forward and backward search completed on the 16 identified studies. These five studies were read in full and a further two eligible studies were identified, resulting in 18 studies being included for review. The screening process is shown in the PRISMA flow diagram in Figure 1.1.

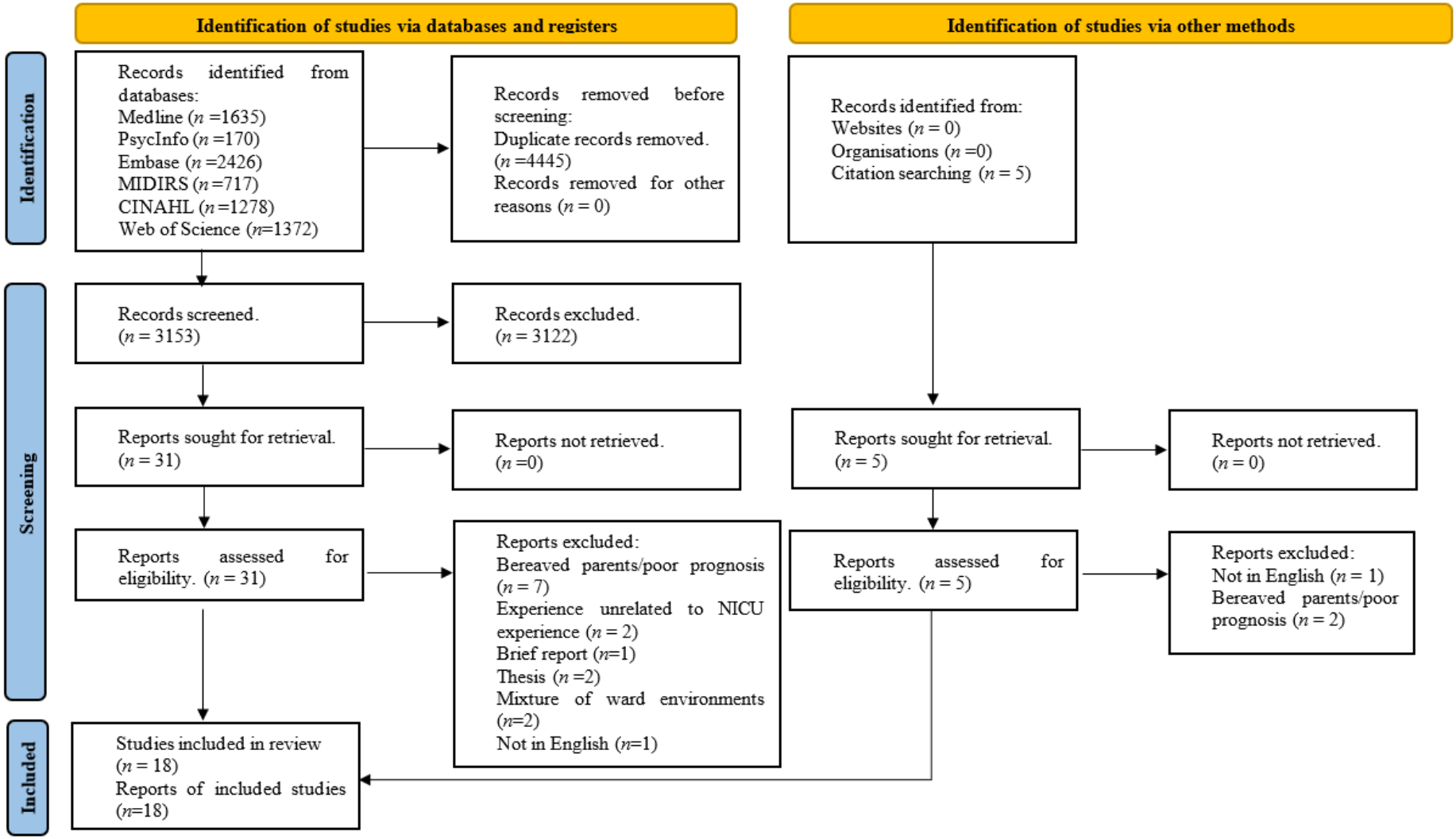

Figure 1.1 - PRISMA flow diagram (Page et al, 2021)

Study characteristics

The characteristics of the 18 included studies are summarised in Table 1.2. Further details are shown in Appendix 1.5, p84. The included studies were published between 2014-2023. Five papers focused on parents' experiences together, seven solely on mothers' and the remaining six exclusively on fathers' experiences. The combined sample across all studies amounted to 540 parents; 77% of the sample were mothers (*n*=414) and 23% were fathers (*n*=126). Ages ranged from younger than 18 to over 55 years old. Ethnicity was often not reported; the five studies that did report ethnicity included White, Black, Turkish, Asian, Indian, Chinese, Malay, and Burmese participants.

Studies were conducted in twelve countries: Brazil (*n*=2), China (*n*=1), Colombia (*n*=1), France (*n*=1), Iran (*n*=3), Israel (*n*=1), Norway (*n*=1), Singapore (*n*=1), South Korea (*n*=1), Turkey (*n*=3), Uganda (*n*=1), USA (*n*=2). Three studies focused on parents' experience of NICU during the COVID-19 pandemic.

Of the 13 studies where it was reported, eight took place while the infant was still in the NICU, with four recruiting after the infant was discharged. One study (Namusoke et al., 2021) included both mothers with infants in NICU and those post discharge. Across the studies, there was a wide time range from having an infant admitted to NICU, with two papers including parents whose infant had been admitted for a minimum of 24 hours to one study including a father who had an infant in NICU 19 years prior to interview (Barton et al., 2021).

Semi-structured interviews were used in most of the included studies (*n*=15). One study used both semi-structured interviews and focus groups (Namusoke et al., 2021). Participants in the semi-structured interviews were excluded from the focus groups, therefore there was no overlap of participants. One study used narrative interviews (Cinar et al., 2017), and another phenomenological interviews (de Cássia de Jesus Melo et al., 2014). Only one study used data from open-ended questions gathered via an online survey (Kim, 2020).

A mixture of data analysis methods were used. Ten studies used Thematic Analysis, one used Grounded Theory (Osorio Galeano and Salazar Maya, 2021), one Narrative Analysis (Shoshi et al., 2022), one Van Manen's phenomenological methodology (Gundogdu et al., 2022), one Interpretative Phenomenological Analysis (IPA) (Dadkhahtehrani et al., 2018) and one Heideggerian Methodology (de Cássia de Jesus Melo et al., 2014). Three studies used Content Analysis (Nazari et al., 2020, Pinar et al., 2020, Urbanosky et al., 2023) and one failed to report their data analysis methodology (Koliouli et al., 2016).

Table 1.2 - Characteristics of included studies

Study	Citation & Country	Dates of data collection and location	Study Sample (No. of participants/Demographic information, how long infant had been in NICU)	When in the NICU journey did study take place	Data collection method and Analysis	Core Themes
S1	Barton et al, 2021 USA	September 2018-NR 6 NICUs and two NICU transfers ward	Fathers (*n*=6) Age range (25-55+ years old) Ethnicity: White (*n*=5) Black (*n*=1) One infant (*n*=4) Twins (*n*=1) Triplets (*n*=1) Infant hospitalised for >7 days	Post discharge-3 weeks to 19 years	Semi-Structured interviews Thematic Analysis	1. Horrible Storm. 2. Piece by Piece. 3. I'm the father. 4. The gift of Support. 5. Little fighters.
S2	Cecagno et al, 2017 Brazil	November 2017-January 2018 One NICU in a teaching hospital in South Brazil.	Mothers (*n*=5) Age range (23-41 years old) First experience of the NICU. Infant hospitalised for >3 days	72 hours-42 days postpartum.	Semi-Structured interviews Thematic Analysis	1. The experience of mothers of premature children hospitalised in the neonatal intensive care unit. 2. Mothers' perceptions of the care received by the team in the neonatal intensive care unit.
S3	Cinar et al, 2017 Turkey	January 2009 One state hospital NICU.	Fathers (*n*=7) Age Range (22-43 years old) Turkish (*n*=7) Muslim (*n*=7) First time fathers (*n*=4)	NR	Narrative interviews. Thematic Analysis	1. Suddenly being in a situation never reflected on. 2. First consider the baby.

			Fathers with 2 children (*n*=2) Fathers with 3 children (*n*=1)			3. Increasing of family responsibility. 4. Information requirements. 5. Needing to share experience with someone who can understand.
S4	Dadkhahtehrani et al, 2017 Iran	December 2013-January 2014 One NICU in Qom, Iran	Fathers (*n*=6) Age Range (23-42 years old)	Infant in NICU.	Semi-structured interviews Interpretative Phenomenological Analysis (IPA)	1. Abandonment and helplessness. 2. Anxiety and confusion 3. Development and self-actualization.
S5	De Cassia et al, 2014 Brazil	March-May 2010 One NICU of a public university hospital in Rio De Janeiro.	Mothers (*n*=9) First 5 days of their NICU experience.	Infant in NICU	Phenomenological Interviews Heideggerian methodology	1. Being afraid of the environment and initially touching the child. 2. Being received in the unit. 3. The chronological period. 4. The monitoring of the baby's improvement.
S6	Gundogdu et al, 2022 Turkey	April-October 2019 NR	Parents (*n*=15) (Mother (*n*=11) Father (*n*=4) First time parent (*n*=8) More than one child (*n*=7) Age range (20-36) First NICU experience Infant hospitalised for >24 hours	Infants in NICU	Semi-structured interviews Van Manen's Hermeneutic Phenomenological Methodology.	1. Having a preterm baby 2. Intensive care experience 3. Feelings and expectations towards nurses. 4. Emotions about discharge and home care.
S7	Kim, 2020 South Korea	November 2017-January 2018.	Mothers (*n*=232) Infant had to be in NICU >7 days.	Mothers were <18 months postpartum.	Open ended questions. Thematic Analysis	1. Family-friendly environment. 2. Relationship- based support.

		49 tertiary hospitals in South Korea.				3. Information and education-based support 4. System-level change.
S8	Koliouli et al, 2016 France	March 2013-April 2014. One university Hospital NICU.	Fathers (*n*=48) Age range (27-52 years old) Infant admitted to NICU for >1 week	NR	Semi structured interviews NR	1. Relationship with infant 2. Feelings as a father 3. Relationship with medical staff 4. Relationship with partner 5. Family support.
S9	Kyno et al, 2021 Norway	Autumn 2020 NR	Parents (*n*=13) (Mother (*n*=9) Father (*n*=4) First time parents (*n*=7) More than one child (*n*=3) Infants had been hospitalised for > 14 days. COVID-19	Post discharge.	Semi-structured interviews Thematic Analysis	1. Life impacting COVID-19 regulations 2. Exceptional times 3. Struggling to become a family.
S10	Namusoke et al, 2021 Uganda	NR One NICU in Mulago	Mothers (*n*=51) Age range: <18 (*n*=5) 19-25 (*n*=19) 26-35 (*n*=24) 36-45(*n*=3)	Infant in the NICU for interviews. Post discharge for focus groups.	Semi-structured interviews and Focus groups. Thematic Analysis	1. Uncertainty about the survival of a preterm baby. 2. Feeding challenges of a preterm baby 3. Worriers about care of the baby after discharge. 4. Communication gap between mothers and nurses and the perceived insensitivity of nurses.

						5. Community acceptability and distain for preterm babies. 6. Financial challenges of having a preterm baby.
S11	Nazari et al, 2020 Iran	2016 2 different NICUs	Mothers (*n*=35) Age range (18-40 years old). Infant in NICU for >4 days	Infant in NICU.	Semi structured interviews Conventional Content Analysis	1. Perceived concerns. 2. Being hopeful.
S12	Osorio Galeano & Salazar Maya 2021 Columbia	April-October 2020 NR	Parents (*n*=12) (Mother (*n*=9) Father (*n*=3) Age range (20-52 years old) One infant (*n*=10) Twins (*n*=1) Triplets (*n*=1)	Post discharge-15 to 120 days.	Semi-structured interviews Grounded Theory	1. Needing information 2. Limiting interaction with the children. 3. The pandemic adding to fears. 4. Limited support after discharge.
S13	Pinar, 2020 Turkey	January-May 2016 One tertiary hospital NICU	Mothers (*n*=25) Age range (20-42 years) Infant in NICU for >3 days COVID-19	NR	Semi-structured interviews Content Analysis	1. The emotional and psychological difficulties of having a premature newborn. 2. Lack of self-confidence. 3. Maternal- newborn interaction. 4. Maternal-health provider's interaction and expectations.
S14	Shahkolahi et al, 2018 Iran	September 2015-February 2016 2 hospitals in Iran	Fathers (*n*=13) Age range (28-37 years old) Infant in NICU for >24 hours.	Infant in NICU.	Semi-structured interviews Thematic Analysis	1. Emotions and responsibilities. 2. Information needs 3. Beliefs

S15	Shoshi et al, 2022 Israel	March-April 2020 Large level 3 NICU.	Mothers (*n*=12) Age range (21-41 years old) Jewish (*n*=11) Muslim (*n*=1) First time mothers (*n*=7) Length of stay in hospital (7-176 days) COVID-19	Infant in NICU	Semi-structured interviews. Narrative Analysis	1. Expectations vs. reality and the need to constantly adapt. 2. Challenges related to COVID-19 3. Coping resources.
S16	Urbanosky et al, 2023 USA	January-June 2020 Recruitment via 3 support groups.	Fathers (*n*=28) Age range (26-49) Race (white *n*=27) (Asian *n*=1) Length of hospital stay (3-122 days)	Post discharge-2 weeks to 16 years	Semi-structured interviews Content Analysis	1. Vividly recalling experience. 2. Stress with work-life balance 3. Worry about their significant other.
S17	Yang et al, 2017 Singapore	November 2013-February 2014. One tertiary public hospital.	Parents (*n*=8) Mothers(*n*=6) Fathers(*n*=2) First time parents (*n*=5) Ethnicity: Chinese (*n*=2) Indian (*n*=3) White (*n*=1) Malay (*n*=1) Burmese (*n*=1) Length of stay in NICU (10- 105 days)	Infant in NICU.	Semi-structured interviews Thematic Analysis	1. Negative emotions versus positive emotions. 2. Finding ways forward. 3. Nature of the support received from various sources. 4. Need for information and professional support.
S18	Yu et al, 2020 China	January-May 2018	Parents (*n*=15) Fathers (*n*=5) Mothers (*n*=10)	Infant in NICU.	Semi-structured interviews	1. Mixed emotional experiences. 2. Separation from the infant.

		One tertiary hospital in central China	Age range (24-43 years) One baby (*n*=11) Multiple babies (*n*=4) Infant in NICU for > 7 days		Thematic Analysis	3. Obtained support through various sources. 4. Desired more from healthcare professionals
Key: Not Reported (NR)						

Quality appraisal

The critical appraisal of the included studies using the CASP is summarised in Appendix 1.6, p96.

Based on the CASP checklist, the area where quality was most lacking was in relation to Question 6, which asked whether the relationship between the researcher and the participants had been adequately considered. The answer to this question was unclear in two studies (Dadkhahtehrani et al., 2018, Gundogdu et al., 2022), as both papers acknowledged that they held certain biases. However, these biases were not expanded on or discussed in terms of how they influenced the design or subsequent 'write up'. In the remaining 16 studies this was rated as 'no' as there was no reference to the researcher's own role or bias. This can be problematic as researchers can hold specific beliefs and biases which can influence how the data is interpreted and reported, thus impacting any conclusions drawn.

Quality was also lacking in relation to Question 3 and the appropriateness of the research design. In seven of the included studies this was rated 'can't tell' as there did not appear to be any justification of the specific research methodology selected. A rationale regarding the data collection and analysis was provided in six of the seven studies, thus increasing the quality of these papers. Only one study was rated as 'no' for this question (Koliouli et al., 2016). Its lack of a clear rationale for design, recruitment and data analysis undermined the credibility of the results.

Several of the studies had issues with the quality of the data analysis. These were mainly in relation to a lack of information regarding the analysis process. For some it was difficult to ascertain how themes had been derived and developed. There was also a lack of contradictory information presented within the findings. This could, however, have been based on participants reporting similar experiences rather than omissions by the researchers.

Even though there were studies with multiple 'can't tell' and 'no' responses, it was still deemed appropriate to include these studies in the synthesis.

Synthesis

Table 1.2 highlights the core themes found in each included study. Idea webbing was used to explore the relationships within and between themes to inform this synthesis Figure 1.2. The data from each paper was read multiple times to establish themes and grouped together to synthesise the evidence.

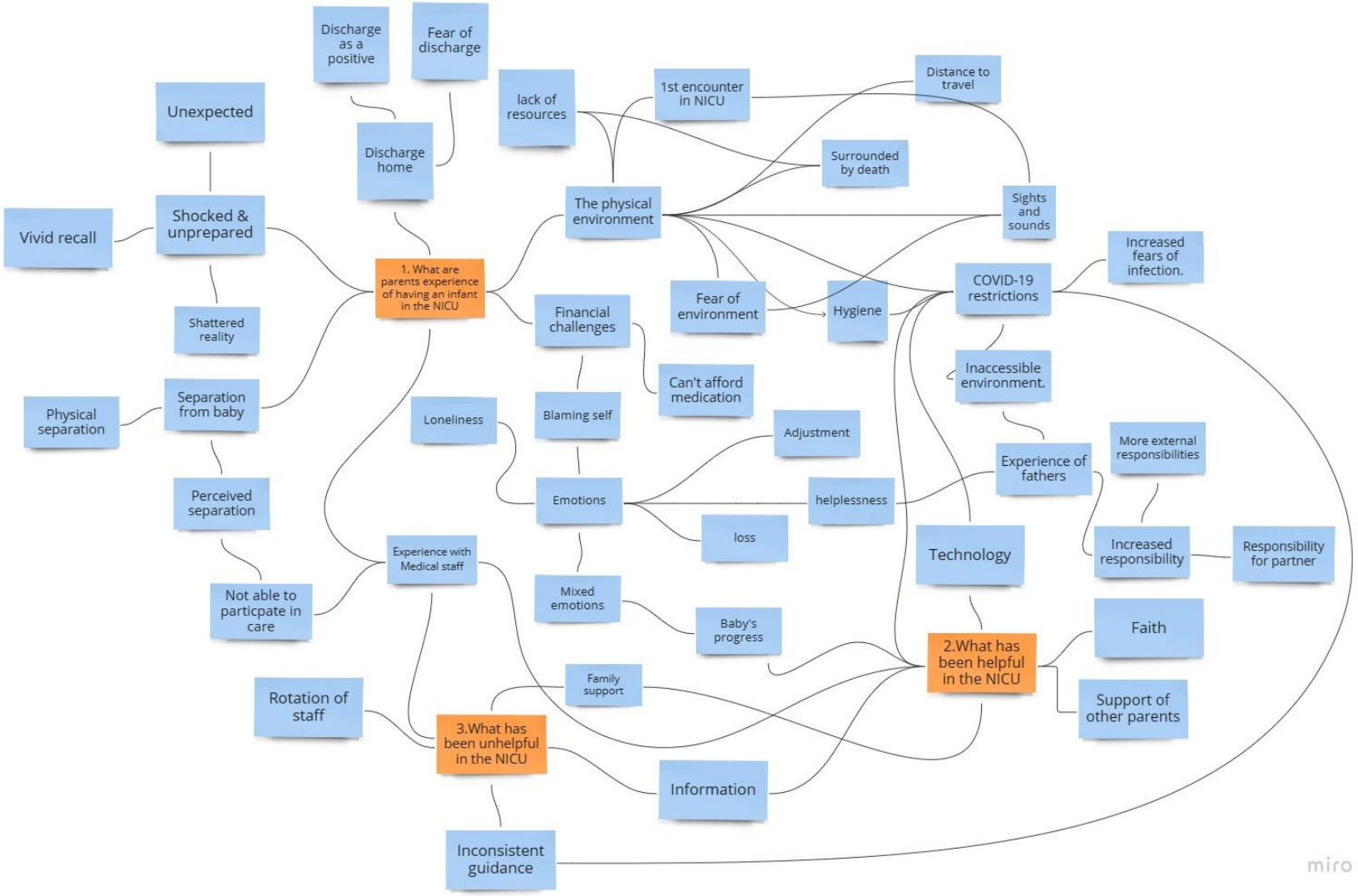

Figure 1.2 - Idea Webbing

The results were then broken down, firstly to focus on how parents experience NICU and secondly to explore what has been helpful/unhelpful for parents in NICU. Quotes from the included studies have been used to illustrate the different themes highlighted in the narrative. First-order constructs (participant quotes) are denoted by "double quotation marks" and second-order constructs (author's interpretations) are denoted by 'single quotation marks'.

What are parents' experiences of having an infant in the NICU?

The physical environment

Unknowing and frightening

How parents experienced NICU was impacted by the physical environment itself (de Cássia de Jesus Melo et al., 2014, Gundogdu et al., 2022, Nazari et al., 2020, Pinar et al., 2020, Kyno et al., 2021, Shahkolahi et al., 2018). Both mothers and fathers experienced the NICU as '*frightening*' owing to the sights and sounds present. It was also reported as being difficult to see the condition of their infants and their infant undergoing perceived '*painful'* procedures. It was specifically noted as being stressful during the first visit when this environment was unfamiliar*; "I have never seen like this place before; doctors, nurses are constantly on the move"*(Pinar et al., 2020). This theme was found across different countries, and both mothers and fathers appeared to struggle with the initial NICU visit and seeing their infants within this setting.

Although all five studies found similar factors contributing to this theme, the use of different analytical methods across these studies means that each will have taken a different epistemological stance and will have considered different elements in the creation of this theme thus making it difficult to draw comparisons between studies in relation to how this theme was reached. Of note, Kyno et al. (2021) conducted their study during COVID-19, and the 'unknown' appeared to be in relation to the unpredictable time and the restrictions placed upon the NICU therefore the timeframe of this study may have influenced this theme rather than the environment itself.

Namusoke et al. (2021) found that a high mortality rate often resulted in infants being moved repeatedly from crib to crib whilst in the NICU, increasing mothers' anxieties as they questioned "*whether my baby would die next?"*. This concept relating to death did not appear in any of the other studies. Due to the use of both semi-structured interviews and focus groups in this study, a more in-depth exploration of this phenomena was explored, thus strengthening the credibility of the theme found and highlighting the uniqueness of this this within this location.

Hygiene concerns

Two studies (Kim, 2020, Nazari et al., 2020) found that NICU hygiene and facilities within the unit impacted on experience. This related to a lack of adequate facilities and inattention to

hygiene. Kim (2020) reported that some mothers did not wish to raise this with staff fearing it would affect their infant's care. Both papers were focused on mothers' experiences, and it may be that this theme arose due to mothers typically spending longer periods of time within the NICU than fathers. Kim (2020) used data from two open-ended questions on an online survey, thus this methodology limited the level of analysis that could occur with this data as there was no contextual or observed data. This therefore makes it impossible to draw as robust conclusions regarding how hygiene concerns specifically impacted these mothers' experience.

Infection control was raised in relation to the studies conducted during COVID-19 (Galeano and Maya, 2021, Kyno et al., 2021, Shoshi et al., 2022). This appeared, however, to be related to restrictions placed upon visitation, mainly affecting fathers (Kyno et al., 2021). Parents were also fearful that they might contract COVID-19 and were subsequently unable to visit their infant or that there was *'a new possible cause of death'* (Galeano and Maya, 2021) for their infant. All these studies used semi-structured interviews, thus allowing participants to discuss their NICU experience however each study used a different type of analytical process. Due to this and the differing theoretical and epistemological stances of each process, each study discussed hygiene from a different perspective, making it difficult to draw a consensus across these three papers in relation to how hygiene concerns during COVID-19 impacted parents' NICU experience.

Financial concerns

Four studies discussed the financial concerns that parents faced when their infant was in NICU (Dadkhahtehrani, et al., 2018, Namusoke et al., 2021, Pinar et al, 2020, Shahkolahi et al., 2018).

Three studies described how the financial costs of having an infant in NICU was a source of stress (Dadkhahtehrani, et al., 2018, Namusoke et al., 2021, Shahkolahi et al., 2018). One study in Uganda (Namusoke et al., 2021) described how the medications and equipment required for care was not always on the '*essential drug list'* meaning families must source this privately, at high cost.

The two other studies (Dadkhahtehrani, et al., 2018, Shahkolahi et al., 2018) were both set in Iran and described the extensive hospitalisation costs and how this effected NICU experience for father, with Dadkhahtehrani et al. (2018) describing how fathers felt they required extra support from the Government and often did not know how they would afford the costs..

However, Pinar et al. (2020) discussed finances in the context of *'emotional distress'* and described how one mother blamed herself for her baby's NICU admission due to her financial situation; "*If my economic situation were good, my baby would develop better. I could not take care of myself enough. She has developmental delay, because of me".* This concept did not appear to be present in any other studies and may highlight the different ways in which mothers

may blame themselves for their infants' admission. However due to Pinar et al. (2020) lack of methodological information, it is difficult to ascertain exactly how this theme was developed.

All these studies were conducted when parents still had an infant in NICU, and this theme did not appear in the studies conducted post-discharge. It may be possible that this was less relevant to parents once their infant was discharged.

Heightened emotions in the NICU environment

All the studies discussed the emotional impact an admission to NICU has on parents; Emotions ranged from loneliness and isolation (Kyno et al., 2021, Pinar et al., 2020) to hope and happiness (Barton et al., 2021, Cinar et al., 2017, Koliouli et al., 2016, Nazari et al., 2020, Yang et al., 2017) with many studies reporting a range of different emotions during a parent's time in NICU.

Shocking and unprepared

Several studies (Barton et al., 2021, Cecagno et al., 2020, Cinar et al., 2017, Dadkhahtehrani et al., 2018, Gundogdu et al., 2022, Pinar et al., 2020, Shoshi et al., 2022, Urbanosky et al., 2023, Yang et al., 2017, Yu et al., 2020) discussed how an infant's admission to NICU was a shock for which parents had not felt prepared. Interestingly, one study (Urbanosky et al., 2023) discussed how this experience stayed with fathers for a number of years following NICU admission.

Mothers also felt loss in relation to practices 'expected' prior to a birth and following delivery, such as baby showers and family parties (Cecagno et al., 2020, Shoshi et al., 2022). This loss appeared to continue throughout their time in the NICU which was not reported in studies focusing on fathers' experiences.

Other studies reported how parents viewed their infant's admission to the NICU as a shock (Cinar et al., 2017, Dadkhahtehrani et al., 2018, Pinar et al., 2020, Yang et al., 2017, Yu et al., 2020), resulting in parents feeling *'sadness and guilt'* (Pinar et al., 2020, Yang et al., 2017, Yu et al., 2020).

Yu et al. (2020) reported that for parents these feelings were intrinsically linked to the infant's entire NICU stay. However, this study was set in China where visitation practices are different, with parents only visiting to receive medical updates from staff rather than to see or interact with their infant. This may have influenced this result as other studies (Pinar et al., 2020, Yang et al., 2017) discussed how parent's journey through NICU often led to a reduction in negative emotions, with parents feeling more confident as time progressed. It could therefore be suggested that in countries where parents are allowed to interact and visit their infant regularly this helps to build confidence and reduce negative emotions.

Dadkhahtehrani et al. (2018) found that for fathers, an infant's premature birth had increased feelings of uncertainty about the future and their role as fathers. They reported that fathers felt their '*dreams had been ruined'* in relation to the birth of a healthy infant, and this was especially true, with fathers who had experienced infertility issues. As part of the process of Interpretative Phenomenological Analysis (IPA), Dadkhahtehrani et al. (2018) spent time within the NICU to deepen their understanding of these father's experiences and gain their trust. It may be through this process that the fathers felt able to discuss these more personal issues relating to infertility and this may be viewed as a strength of the analytical method used within this study.

Loneliness and Isolation

Although Pinar et al. (2020) described a theme as '*feeling isolation towards the NICU setting'* this appeared to cover a range of different emotions experienced by mothers and was not specifically in relation to isolation. It was also difficult to ascertain how this theme was developed due to poor reporting of methodological issues, therefore Pinar el al., (2020) could not be included within this concept.

Kyno et al. (2021) and Shoshi et al. (2022) reported that isolation was experienced by mothers during the COVID-19 pandemic as there was a *'lack of a present father'* to share this experience with (Kyno et al., 2021) and they felt the *'burden of responsibility alone'* (Shoshi et al., 2022). It is possible that this theme was found due to the situational factor of the COVID-19 pandemic and the restrictions created within the wider system. During this time, restrictions were in place that limited or stopped fathers from being able to visit the NICU. As this theme did not appear in other studies conducted outside of the pandemic timeframe, it may be possible to assume that this theme was because of the wider service system and context rather than the specific NICU environment.

Interestingly, two studies (Namusoke et al., 2021, Shahkolahi et al., 2018) discussed worrying about *'what others thought'*. Shahkolahi et al. (2018) found that fathers were worried about *"What people might say"* whereas Namusoke et al. (2021) reported that mothers felt that their community '*did not give as much value to preterm infants'.* This affected parents' ability to discuss their NICU experience, thus isolating them from social support. Within Iranian and Sub-Saharan Africa there is social stigma that exists around having a premature or an infant with abnormalities, therefore it may have been possible that this theme was found due to socio-cultural factors within these countries.

Hope and happiness

Fathers appeared to experience feelings of happiness at becoming a father (Barton et al., 2021, Cinar et al., 2017, Koliouli et al., 2016) however this was also experienced alongside anxiety and fear about the premature birth and uncertainty regarding their NICU stay and the infant's health.

Mothers' hope appeared to be in relation to their infant's progress through the unit towards discharge (de Cássia de Jesus Melo et al., 2014, Nazari et al., 2020, Yang et al., 2017).

Separation from baby

Within the NICU, parents experienced a feeling of being '*separated from their infant'* thus impacting their experience.

At times, this was due to a physical separation, where parents couldn't visit owning to the visitation guidelines within their country (Kim, 2020, Yu et al., 2020) or because of other commitments/ responsibilities outside of the NICU (Barton et al., 2021, Cinar et al., 2017) which impacted on the time they could spend within the unit. The latter tended to be experienced by fathers, and was exacerbated during the COVID-19 pandemic where visitation for fathers was banned, thus impacting on father's perceived attachment to infant (Galeano and Maya, 2021, Kyno et al., 2021).

This separation was also reported as a 'perceived' separation, where parents felt unable to fulfil their role as parents within this environment (Gundogdu et al., 2022, Pinar et al., 2020, Shoshi et al., 2022, Yu et al., 2020) resulting in parents feeling like *'spectators'* and reporting low levels of confidence in their abilities as parents (Yu et al., 2020). Again, this theme was found across different analytical methods, however Van Manen's analysis (Gundogdu., et al, 2022) and narrative analysis (Shoshi., et al 2022) are more likely to provide a greater understanding of this phenomena than content analysis (Pinar., 2020) owning to more emphasis being placed on understanding an individual's unique experience within their unique context in these analytical methods.

Discharge home

While in the NICU, parents appeared to consider the future and the discharge of their infant. This was experienced positively (Nazari et al., 2020, Yang et al., 2017) and negatively (Gundogdu et al., 2022, Namusoke et al., 2021, Shoshi et al., 2022, Yang et al., 2017, Galeano and Maya, 2021).

Mothers viewed discharge positively, as a way of *"getting rid of the long hospital stays"* and getting back to their family (Nazari et al., 2020). The idea of discharge also gave parents *'energy'* to keep going (Yang et al., 2017). This was contradicted with parents discussing their fears related to discharge especially in relation to being able to care for their infant and take over responsibilities (Gundogdu et al., 2022, Namusoke et al., 2021, Shoshi et al., 2022, Yang et al., 2017, Galeano and Maya, 2021). Galeano and Maya (2021) specifically noted that in relation to COVID-19, parents had concerns regarding adequate follow-up due to restrictions, highlighting another consideration added by the COVID-19 pandemic.

Experiences specific to fathers

The studies that focused purely on fathers' experiences of the NICU highlighted two key theme unique to fathers. All six studies reported that fathers felt a heightened responsibility to care for their partner/wife ensuring she was supported during the infant's admission. In two studies (Barton et al., 2021, Dadkhahtehrani et al., 2018) participants were involved at the data analysis stage and reviewed transcripts as a way of ensuring trustworthiness, thus increasing the credibility and methodological rigor of these studies and ensuring that the themes created are true to the participant's experience.

This heightened responsibility was described as *'being the strong one'* (Urbanosky et al., 2023) and being part of *"a team together"* (Barton et al., 2021). One study reported that by supporting their wives, fathers felt an increased intimacy within the martial relationship (Dadkhahtehrani et al., 2018). Urbanosky et al. (2023) -which included a father who was 19 years post NICU discharge- reported that fathers still *'vividly recalled'* their NICU experience with one father remembering thinking; *"I could walk out of this hospital without my wife or our baby*". As this study used content analysis, less emphasis was placed on understanding the father' unique experience and therefore this study did not provide further details regarding the specific elements of the experience that were recalled.

Fathers also felt pressure to manage the other responsibilities outside of the NICU, such as work, and other family commitments (Barton et al., 2021, Cinar et al., 2017, Dadkhahtehrani et al., 2018, Koliouli et al., 2016, Urbanosky et al., 2023). This added to the stress fathers experienced during this time as well as the time that they had available to be on the unit.

What has been helpful/unhelpful for parents

Only one study (Urbanosky et al., 2023) did not include any data pertaining to what has been helpful/unhelpful to parents.

Support

Support was described as crucial for parents in 15 studies (Barton et al., 2021, Cecagno et al., 2020, Cinar et al., 2017, de Cássia de Jesus Melo et al., 2014, Galeano and Maya, 2021, Gundogdu et al., 2022, Kim, 2020, Koliouli et al., 2016, Kyno et al., 2021, Nazari et al., 2020, Pinar et al., 2020, Shahkolahi et al., 2018, Shoshi et al., 2022, Urbanosky et al., 2023, Yang et al., 2017). Again, the methodological heterogeneity of the studies here may have resulted in different ways that support was defined and considered in the different studies thus influencing the conclusions that can be drawn across studies. There were also numerous locations involved in these studies, which again due to the heterogeneity of the services and resources available may also influence to what extend conclusions can be drawn across studies.

Within the NICU, parents' experiences relied heavily on their interactions and communication with health-care providers. All 15 studies reported positive relationships were established with health-care professionals who were compassionate, trusting and provided adequate support and information. Good health-care support allowed parents to feel their infants were well looked after and allowed them to take breaks and go home to rest (Cecagno et al., 2020, de Cássia de Jesus Melo et al., 2014, Shoshi et al., 2022).

Three studies discussed parents' poor experience with health-care professionals while in the NICU (Dadkhahtehrani et al., 2018, Namusoke et al., 2021, Yu et al., 2020) where they felt ignored, unsupported and misinformed. This impacted on the trust and resulted in them feeling dissatisfied within this environment.

Having support from other parents who were experiencing a similar situation to themselves helped parents navigate the NICU. They found it *"comforting"* (Yang et al., 2017) and expressed how other parents understood their situation *'where outsiders couldn't'* (Shoshi et al., 2022). This support was also viewed as beneficial when it was provided via text message or online (Kim, 2020, Yang et al., 2017). During the COVID-19 pandemic, support from other parents was vital owing to their limited access to their usual support networks due to pandemic restrictions (Kyno et al., 2021, Shoshi et al., 2022).

Family support was also reported as beneficial both practically and emotionally (Barton et al., 2021). One study (Yang et al., 2017) found support from the wider community beneficial as it felt like they were *'not journeying alone'.* The idea of the wider community was only found in this paper and may reflect the collectivist culture within Singapore.

Interestingly, Kyno et al. (2021) highlighted that the pandemic allowed parents to enjoy the *'overall social quietness'* where they could focus on their infants without welcoming visitors. Koliouli et al. (2016) was the only study to state that family support was unhelpful for a small proportion (*n*=9) of the fathers. They found family contact too difficult as the process of explaining the infants' health status and presentation was deemed distressing and emotional, however due to the poor methodological reporting and lack of information pertaining to the data analysis process, the findings that can be drawn from this study are questionable and cannot be applied outside of this study.

Faith

Six studies reported that faith and spirituality helped parents cope within NICU (Barton et al., 2021, Dadkhahtehrani et al., 2018, Nazari et al., 2020, Shahkolahi et al., 2018, Shoshi et al., 2022, Yang et al., 2017). Shoshi et al. (2022) used a narrative approach, which allowed them to consider how these mothers' experiences were shaped by their identities as well as their cultural and social

circumstances, thus resulting in a more nuanced understanding of the importance of faith to these mothers, especially during the COVID-19 pandemic. They provided detailed of how this faith helped parents to cope, as opposed to Nazari et al, 2020 who used content analysis and reported the theme of 'prayers for recovery' however did not expand on how this supported parents within the NICU.

Technology

Three studies (Galeano and Maya, 2021, Kyno et al., 2021, Yu et al., 2020) found that the use of technology was helpful for parents when their infants were in the NICU. Where parents' access to NICU was restricted due to cultural issues (Yu et al., 2020), they benefitted from message updates provided by staff. Technology was used more during the pandemic as a way of aiding communication and sharing information about infants in NICU (Galeano and Maya, 2021, Kyno et al., 2021). However, both studies highlighted that although this was beneficial, parents still felt a yearning to be near their infant and technology did not replace the need for actual physical contact.

Information

The need for clear, comprehendible, and up-to-date information about their infant was reported in four studies (Galeano and Maya, 2021, Koliouli et al., 2016, Shahkolahi et al., 2018, Yang et al., 2017). Parents wanted to have general information about their infant's care and treatment on a regular basis. Shahkolahi et al. (2018) found that fathers also would have found it helpful to have information about NICU early on in their partner's pregnancy to prepare for this experience.

Kim (2020) described the theme of *'family-friendly environment'* as being helpful. This appeared to focus on support staff as well as unrestricted 24-hour access to the NICU which mothers viewed as helping with bonding and the transition to motherhood. 24-hour access was not discussed in other studies, and this again may be due to the cultural context of South Korea where this study was conducted. However, due to the methodological approach, the themes found here are superficial in nature and it could be that this theme would not be found if another methodological approach, such as one to one interviews where probes and exploration can occur with participants.

Information issues were highlighted in six studies (Cinar et al., 2017, Galeano and Maya, 2021, Kim, 2020, Shoshi et al., 2022, Yang et al., 2017, Yu et al., 2020). When insufficient information was provided this was deemed unhelpful by parents and led them to feel less confident in themselves and the health-care providers. When parents did not receive adequate information they accessed the internet for answers (Kim, 2020, Yu et al., 2020) which was unhelpful as it was difficult to *"distinguish what was right or wrong"* (Yu et al., 2020).

One study (Namusoke et al., 2021), found that inconsistent and unclear communication was unhelpful, as it resulted in mothers feeling unclear about how their baby's care should progress. This was highlighted in the focus groups where infants were discharged, highlighting the way communication can affect the long-term care of the infant as well as parents' experience and confidence.

Lack of involvement in care

Three studies conducted in different Asian countries (Kim, 2020, Yang et al., 2017, Yu et al., 2020) found that parents reported it to be unhelpful when they were separated from their infant and were unable to be involved in their care. Parents reported low self-confidence, worries about attachment and a desire to provide more 'hands-on' support (Kim, 2020, Yu et al., 2020). Yang et al. (2017) reported how mothers described providing kangaroo care helped them to feel connected to their infant.

Discussion

The purpose of this review was to synthesise the available recent evidence on parents' experiences of having an infant in the NICU. Similar themes to the previous review by Al Maghaireh et al. (2016) were found here, however, several other themes were also discovered.

This review highlighted financial concerns adding to parents' stress and their overall experience of NICU. Both mothers and fathers worried about how they would pay for their infant's care in countries where payment was required, as well as one study highlighting how mothers may attribute blame to their infant's admission based on their financial situation prior to admission. This highlights a two-fold issue, firstly that admission to a NICU may add a financial burden, as well as indicating that the societal issue of poverty impacts and influence this experience.

At least half of the world's population cannot obtain essential health services, with more people each year being pushed into poverty because they are required to pay for essential health care without adequate support (World Health Organisation (WHO), 2017). There are wide gaps that exist in healthcare provision across Sub-Saharan Africa and Southern Asia, thus impacting on available access to provisions. One example of this is that up until 2014, there was no dedicated facility or staff to care for neonates that were born early or sick in Uganda, resulting in adequate care and treatment or no treatment at all. As well gaps across countries, there are also inequalities that exist within countries, with poorer households having higher rates of physical health conditions and lower life expectancy compared to higher income households (Lone et al., 2021). As a parent, the idea of not being able to afford to look after your newborns' health must be devastating and impact on your identity as a parent. Although consideration should be made by professionals regarding how best to support parents to lessen the financial burden of a NICU

admission, this is not always possible due to the inequalities in healthcare provision across the globe. This highlights a wider system failing and promotes the need for more universal health coverage to promote better healthcare outcomes and reduce poverty.

Hygiene concerns were not shown before and this may be due to the countries where the included studies were conducted, or the inclusion of COVID-19 studies within this review. Poor hygiene increased parents' worries about their infant's health and highlighted how this could interfere with relationships to staff. In the context of COVID-19, parents also became worried about the new risk they posed to their infant, viewing themselves and staff as the hygiene concerns rather than the wider NICU environment. Furthermore, inadequate facilities also effected the experience. As parents can spend long periods of time within the NICU, where possible, there should be access to adequate facilities to make their experience more comfortable. This could include a private space within the unit, with comfortable chairs and refreshments to allow parents a quiet space. However, as discussed above, healthcare provision and available resources across the globe differs and this provision may not be possible in all locations.

Although the scope of this review was to examine the experience of parents within the NICU, several studies highlighted how their infant's discharge was considered by parents throughout their NICU stay, thus impacting on experience. The studies conducted during COVID-19 highlighted how a lack of discharge support due to the restrictions imposed increased parental' anxiety. Garne Holm et al., 2018 found that where parents had additional support following discharge, they felt more empowered to care independently for their infant. Providing parents with clear comprehendible information regarding the discharge process and post-discharge support may help to reduce parents' worries while they are in NICU and allow them to feel confident for discharge. It could also be suggested that links with community resources are established while parents are in NICU to allow a continuity of care and support.

This review included studies from a range of different countries, the inclusion of studies from a wide range of countries- including Asia & Africa- allowed for different cultural perspectives to be considered and highlighted how different cultural contexts can influence the experience of NICU. The studies conducted in Iran and Uganda highlighted how parents may not share their experience with the wider community for fear of judgement and shame, which is shown within the wider literature (Heidari et al., 2012, Nalwadda et al., 2023). However within Singaporean culture the opposite was found, with parents seeking support for their wider community. These cultural constraints will undoubtably effect the NICU experience and how parents cope within this environment. Professionals working within these environments need to be aware of the cultural factors that exist for an individual and provide support with this in mind. This may

include education for parents regarding NICU admission and emotional support to reduce the stigma and misinformation that may exist within some cultures.

Also, the inclusion of studies conducted in Asia, (Kim, 2020, Yang et al., 2017, Yu et al., 2020) highlighted how restricted to no access to the NICU impacted on parents' experiences and delivery of FFC. The study conducted in China (Yang et al., 2017), where there was no access for parents to the NICU, highlighted how these parents felt separated, both physically and metaphorically from their babies, resulting in low-confidence and worries regarding discharge. There may, however, be challenges in implementing FFC within some countries due to complex and diverse political, social and cultural issues (Vetcho et al., 2023). It may be suggested that countries where the FFC approach cannot be fully implemented then adaptations should be made to encourage as much parent-infant involvement as possible. Although these studies discuss technology aiding their experiences, when compared with the studies from COVID-19 where participants experienced both 24-hour access and technology support, technology did not replace the need for physical contact, highlighting how vital it is for parents to be allowed access to the NICU and their infant.

Review limitation and risk of bias

The concept of 'experience' is difficult to define, and different studies conceptualised experiences using different themes and terminology. In this review, there was a requirement to synthesis these experiences in a coherent and logical way to inform the narrative synthesis. However, due to the lead researcher's own bias or interpretation, this might have resulted in certain themes within the included studies being mis-interpreted, influencing the results presented here. The involvement of a second reviewer in the data extraction and quality assessment process as well as the inclusion of both first and second-order constructs sought to minimise this risk of bias.

Although this study set out to examine other caregivers' experiences (e.g. Grandparents, adoptive parents, surrogates), this was unfortunately not possible due to the lack of available research in this area.

It is possible that some of the studies may have included same sex parents, however this was not explicitly stated in any of the included studies, and it is therefore assumed that same sex parents were not included in this review. With advances in reproductive medicine and expansion in legal rights for same-sex couples, there has been an increase in the number of same-sex parents (Logan, 2020). Same-sex relationships and family dynamics do not simply mirror their heterosexual counterparts and have their own challenges, for example legal barriers and homophobia/stigma which may impact on their experience and needs within this context.

This review only included published studies, and there may have been further studies identified within 'grey literature' that were missed due to this criterion. Inclusion of grey literature may have minimised publication bias and maximised inclusivity (Paez, 2017).

Although narrative synthesis is capable of synthesising heterogenous studies, there was a range of different methodologies and data analysis methods used and it has been suggested that grouping together findings may obscure the diversity of the studies and may make it difficult to draw similarities across studies, which may represent a weakness in the current review (Lucas et al., 2007). Furthermore, there was the inclusion of a study (Kim, 2020) where data was gathered using questions from an online survey. The contribution of this study was considered throughout the synthesis as this methodology does not provide the same level of depth into the nuances, complexities and context of phenomena that interviews, and focus groups provide thus impacting on the comparison that can be made between this study and the other included studies in this review. Three studies used content analysis (Nazari, et al 2020, Pinar, 2020 and Urbanosky, et al 2023), where code frequency is central to the analytical process, again this analytical process does not consider the more nuanced understanding of the lived experience that IPA, narrative analysis and Thematic Analysis offer. Therefore, although similar themes were highlighted, these studies contributed less to the synthesis as they were unable to provide the same depth regarding lived experience that the other studies could provide.

Study quality was also mixed, and although no studies were excluded on this basis, some were appraised as lower quality and lacking important methodological information. This influenced the extent to which some studies contributed during the synthesis, with those with lower methodological rigor (Cecagno et al., 2020, de Cássia de Jesus Melo et al., 2014, Koliouli et al, 2016, Pinar, 2020, Urbnosky, et al 2023) contributing less.

Review Strengths

Previous reviews have focused solely on mothers, fathers, or parents' experiences separately whereas this review synthesised all these experiences together. This allowed for a more comprehensive synthesis and for difference between mothers' and fathers' experiences to be highlighted. It showed that fathers were more likely to have issues regarding visitations, due to their other commitments outside of the unit, and experience feelings of uncertainty regarding their role as a father. This appeared to be exacerbated when there was limited contact with the infant and was perceived as impacting on the parental-infant bond. It also highlighted that fathers worried about the mother and infant's health, especially in the initial stage, meaning that it is vital that professionals provide support and information regarding the health status of their family to fathers, especially in this initial stage of admission. Mothers appeared to experience a sense of loss in relation to the practices that they expected prior to a birth and following delivery, such

as baby showers and family parties and this appeared to continue throughout their time in the NICU. They also appeared to focus more on the discharge of their infant and it highlighted that mothers may attribute blame to themselves in different ways in relation to their infants' admission. This highlights that mothers and fathers have different experiences within the NICU, and tailored support should therefore be offered to meet these needs.

This review also highlighted gaps in the literature in relation to wider caregivers and same-sex parents and highlighted future areas of study required.

The inclusion of studies from a wide range of countries- including Asia & Africa- allowed for different cultural perspectives to be considered and highlighted how different cultural contexts can influence the experience of NICU. The heterogeneity in the location of the included studies also highlights how parents exist within different system levels, which ranges from individual to the macrosystems (Bronfenbrenner, 1992). Professionals are required to look beyond the individual and consider how these systems interact and influence one another as this will inevitably effect the experience of the parents within the NICU.

Future recommendations and conclusions.

Given the lack of literature surrounding other caregiver and same-sex parents' it would be useful for future research to examine their NICU experience. It is likely that these caregivers will have different experiences/needs within the NICU than the themes highlighted here. It is important to identify these to allow professionals to provide the appropriate support and ensure their needs are met within this environment.

This review also focused on parents who were not expecting NICU admission, and it may be that parents who are aware their infant will require NICU care might experience this differently. This would be interesting to examine as it may highlight helpful ways in which all parents could be supported to become aware of the NICU environment during pregnancy. Bereaved parents and studies where prognosis was poor were excluded from this review and again these parents might experience NICU differently to the themes highlighted here.

In conclusion, this review found similar themes to the previous review (Al Maghaireh et al., 2016), but also discovered new themes. There were practical concerns highlighted as impacting the experience for parents; financial and hygiene. These concerns impact on parents' comfort as well as their ability to bond and seek support. Professionals within the unit should be aware of the practical ramifications an infant's admission has on parents and support should be offered where available. Furthermore, the restricted access to the NICU impacts on parents' ability to bond with their infants and feel part of their care. There may be challenges to implementing FFC, however countries where there is still restricted access should consider how they could facilitate

a more ‘hands-on’ experience for parents, as it was highlighted that technology, however useful, does not replace physical contact.

References

ADAMA, E. A., ADUA, E., BAYES, S. & MORELIUS, E. 2022. Support needs of parents in neonatal intensive care unit: An integrative review. *Journal of clinical nursing,* 31(5-6)**,** 532-547.

AFFLECK, G. & TENNEN, H. 1991. The Effect of Newborn Intensive Care on Parents' Pschological Well-Being. *Children's Health Care,* 20**,** 6-14.

AL MAGHAIREH, D. F., ABDULLAH, K. L., CHAN, C. M., PIAW, C. Y. & AL KAWAFHA, M. M. 2016. Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit. *Journal of Clinical Nursing,* 25**,** 2745-56.

BARTON, N., HALL, C. & RISKO, J. 2021. The lived experience of a NICU father: A descriptive phenomenological study. *Journal of Neonatal Nursing,* 27**,** 206-210.

BRONFENBRENNER, U. 1992. Ecological systems theory. *Six theories of child development: Revised formulations and current issues.* London, England: Jessica Kingsley Publishers.

CECAGNO, D., CARDOSO FRÖHLINCH, C. V., CECAGNO, S., MARQUES WEYKAMP, J., BENIGNO BIANA, C. & CORREA SOARES, M. 2020. The experience in a neonatal intensive care unit: Mothers' point of view. *Revista de Pesquisa: Cuidado e Fundamental,* 12**,** 566-572.

CINAR, N., KUGUOGLU, S., SAHIN, S. & ALTINKAYNAK, S. 2017. The experience of fathers having premature infants in the Neonatal intensive care unit. *Open Journal of Pediatrics & Neonatal Care,* 1**,** 8-12.

COOKE, A., SMITH, D. & BOOTH, A. 2012. Beyond PICO:The SPIDER Tool for Qualitative Evidence Synthesis. *Qualitative Health Research,* 22**,** 1435-1443.

CRITICAL APPRAISAL SKILLS PROGRAMME. 2022. *CASP Qualitative Checklist.* [Online]. Available: https://casp-uk.net/casp-tools-checklists/ [Accessed 19th May 2023].

DADKHAHTEHRANI, T., ESKANDARI, N., KHALAJINIA, Z. & AHMARI-TEHRAN, H. 2018. Experiences of Fathers with Inpatient Premature Neonates: Phenomenological Interpretative Analysis. *Iranian Journal of Nursing and Midwifery Research,* 23**,** 71-78.

DE CÁSSIA DE JESUS MELO, R., DE OLIVEIRA SOUZA, Í. E. & DE PAULA, C. C. 2014. The voice of the woman-mother of a premature baby in the neonatal unit: a phenomenological approach. *Online Brazilian Journal of Nursing,* 13**,** 194-202.

FINLAYSON, K., DIXON, A., SMITH, C., DYKES, F. & FLACKING, R. 2014. Mothers' perceptions of family centred care in neonatal intensive care units. *Sexual and Reproductive Healthcare,* 5(3)**,** 119-124.

GALEANO, S. P. O. & MAYA, A. M. S. 2021. Experiences of Parents of Preterm Children Hospitalized Regarding Restrictions to Interact with Their Children Imposed Because of the COVID-19 Pandemic. *Investigacion Y Educacion En Enfermeria,* 39**,** 15.

GARNE HOLM, K., BRØDSGAARD, A., ZACHARIASSEN, G., SMITH, A. C. & CLEMENSEN, J. 2018. Parent perspectives of neonatal tele-homecare: A qualitative study. *Journal of Telemedicine and Telecare,* 25**,** 221-229.

GOVINDASWAMY, P., LAING, S., WATERS, D., WALKER, K., SPENCE, K. & BADAWI, N. 2019. Needs and stressors of parents of term and near-term infants in the NICU: A systematic review with best practice guidelines. *Early Human Development,* 139 104839.

GUNDOGDU, N. A., MERT, Z. T. & GUNDUZ, E. S. 2022. Not being able to hug our baby before the cables: Early experiences of parents with premature babies. *Nursing Forum,* 57**,** 1193-1203.

HEIDARI, H., HASANPOUR, M. & FOOLADI, M. 2012. The Iranian parents of premature infants in NICU experience stigma of shame. *Med Arh,* 66**,** 35-40.

KIM, A. R. 2020. Addressing the needs of mothers with infants in the neonatal intensive care unit: A qualitative secondary analysis. *Asian nursing research.,* 13**,** 327-337.

KOLIOULI, F., GAUDRON, C. Z. & RAYNAUD, J. 2016. Life experiences of French premature fathers: A qualitative study. *The Journal of Neonatal Nursing,* 22**,** 244-249.

KUTAHYALIOGLU, N. S. & SCAFIDE, K. N. 2022. Effects of family-centered care on bonding: A systematic review. *Journal of Child Health Care***,** 13674935221085799.

KYNO, N. M., FUGELSETH, D., KNUDSEN, L. M. M. & TANDBERG, B. S. 2021. Starting parenting in isolation a qualitative user-initiated study of parents' experiences with hospitalization in Neonatal Intensive Care units during the COVID-19 pandemic. *PLoS ONE,* 16**,** 1-17.

LOEWENSTEIN, K., BARROSO, J. & PHILLIPS, S. 2019. The Experiences of Parents in the Neonatal Intensive Care Unit - An Integrative Review of Qualitative Studies Within the Transactional Model of Stress and Coping. *The Journal of Perinatal and Neonatal Nursing*, 33**,** 340-349.

LOGAN, R. 2020. Gay fatherhood in the NICU. *Advances in neonatal care.* , 20**,** 286-293.

LONE, N. I., MCPEAKE, J., STEWART, N. I., BLAYNEY, M. C., SEEM, R. C., DONALDSON, L., GLASS, E., HADDOW, C., HALL, R., MARTIN, C., PATON, M., SMITH-PALMER, A., KAYE, C. T. & PUXTY, K. 2021. Influence of socioeconomic deprivation on interventions and outcomes for patients admitted with COVID-19 to critical care units in Scotland: A national cohort study. *The Lancet Regional Health - Europe,* 1**,** 100005.

LONG, H. A., FRENCH, D. P. & BROOKS, J. M. 2020. Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Science.,* 1**,** 31-42.

LUCAS, P. J., BAIRD, J., ARAI, L., LAW, C. & ROBERTS, H. M. 2007. Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Medical Research Methodology,* 7**,** 4.

MILES, M. S., BURCHINAL, P., HOLDITCH-DAVIS, D., BRUNSSEN, S. & WILSON, S. M. 2002. Perceptions of stress, worry, and support in Black and White mothers of hospitalized, medically fragile infants. *J Pediatr Nurs,* 17**,** 82-8.

NALWADDA, C., TUSUBIRA, A. K., NAMBUYA, H., NAMAZZI, G., MUWANGUZI, D., WAISWA, P., KURINCZUK, J., KELLEY, M. & NAIR, M. 2023. Transition from hospital to home care for preterm babies: A qualitative study of the experiences of caregivers in Uganda. *PLOS Glob Public Health,* 3**,** e0000528.

NAMUSOKE, F., SEKIKUBO, M., NAMIIRO, F. & NAKIGUDDE, J. 2021. "What are you carrying?" Experiences of mothers with preterm babies in low-resource setting neonatal intensive care unit: a qualitative study. *BMJ Open,* 11**,** e043989.

NAZARI, R., MORADI KOOSHA, F., REZAIE, S., AKBARI, N., QOLIZADEH, A. & SABZI, Z. 2020. Experiences of the mothers of infants hospitalized in the neonatal intensive care unit (NICU). *Journal of neonatal perinatal medicine.,* 21**,** 571-579.

NOYES, J., BOOTH, A., FLEMMING, K., GARSIDE, R., HARDEN, A., LEWIN, S., PANTOJA, T., HANNES, K., CARGO, M. & THOMAS, J. 2018. Cochrane Qualitative and Implementation Methods Group guidance series—paper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *Journal of Clinical Epidemiology,* 97**,** 49-58.

OSORIO GALEANO, S. P. & SALAZAR MAYA, A. M. 2021. Experiences of Parents of Preterm Children Hospitalized Regarding Restrictions to Interact with Their Children Imposed Because of the COVID-19 Pandemic. *Investigacion y educacion en enfermeria,* 39**,** 133-147.

PAEZ, A. 2017. Grey literature: An important resource in systematic reviews. *J Evid Based Med*.

PAGE, M. J., MCKENZIE, J. E., BOSSUYT, P. M., BOUTRON, I., HOFFMANN, T. C., MULROW, C. D., SHAMSEER, L., TETZLAFF, J. M., AKL, E. A., BRENNAN, S. E., CHOU, R., GLANVILLE, J., GRIMSHAW, J. M., HRÓBJARTSSON, A., LALU, M. M., LI, T., LODER, E. W., MAYO-WILSON, E., MCDONALD, S., MCGUINNESS, L. A., STEWART, L. A., THOMAS, J., TRICCO, A. C., WELCH, V. A., WHITING, P. & MOHER, D. 2021. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ,* 372**,** n71.

PINAR, A., ERBABA, A., PINAR, G. & TOSUN, H. 2020. Experiences of New Mothers with Premature Babies in Neonatal Care Units: A Qualitative Study. 3**,** 179-185.

POPAY, J., ROBERT, H., SOWDEN, A., PETTICREW, M., ARAI, L., MARK, R., BRITTEN, N., ROEN, K. & DUFFY, S. 2006. *Guidance on the Conduct of Narrative Synthesis in Systematic Reviews* [Online]. https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.178.3100&rep=rep1&type=pdf. [Accessed May 2023].

POPE, C., MAYS, N. & POPAY, J. 2007. *Synthesizing qualitative and quantitative health evidence: a guide to methods. Buckingham: Open University Press*.

PROVENZI, L. & SANTORO, E. 2015. The lived experience of fathers of preterm infants in the Neonatal Intensive Care Unit: a systematic review of qualitative studies. *Journal of Clinical Nursing,* 24**,** 1784-94.

ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH (RCPCH). 2022. *National Neonatal Audit Programme: Annual Report on 2020 data* [Online]. https://www.hqip.org.uk/wp-content/uploads/2022/11/Ref.-369-NNAP-annual-report-Report-FINAL.pdf: Healt Quality Improvement Partnership. [Accessed 27th April 2023].

SHAHKOLAHI, Z., LENJI, Z. M. & JAFARI-MIANAEI, S. 2018. Challenging experiences of the fathers of the premature infants admitted in the neonatal intensive care unit (NICU). *Iranian Journal of Neonatology,* 9(1)**,** 53-59.

SHOSHI, P. H., TUVAL-MASHIACH, R. & BIN NUN, A. 2022. One uncertainty added on top of another: Challenges and resources of mothers of preterm infants during the COVID-19 pandemic. *Frontiers in Psychology,* 13**,** 968192.

UK GOVERNEMENT. 2022. *Parents whose babies require neonatal care to receive paid leave under new law backed by Government* [Online]. https://www.gov.uk/government/news/parents-whose-babies-require-neonatal-care-to-receive-paid-leave-under-new-law-backed-by-government. [Accessed 12th July 2023].

URBANOSKY, C., MERRITT, L. & MAXWELL, J. 2023. Fathers' perceptions of the NICU experience. *Journal of Neonatal Nursing***,** 545-549.

VETCHO, S., ULLMAN, A. J., PETSKY, H., WIROONPANICH, W. & COOKE, M. 2023. Parent and interdisciplinary professional perceptions of family-centered care in Thai NICU: A qualitative study. *Nursing in critical care,* 28(1)**,** 47-55.

WANG, L. L., MA, J. J., MENG, H. H. & ZHOU, J. 2021. Mothers' experiences of neonatal intensive care: A systematic review and implications for clinical practice. *World Journal of Clinical Cases,* 9**,** 7062-7072.

WORLD HEALTH ORGANISATION (WHO). 2017. *World Bank and WHO: Half the world lacks access to essential health services, 100 million still pushed into extreme poverty because of health expenses* [Online]. https://www.who.int/news/item/13-12-2017-world-bank-and-who-half-the-world-lacks-access-to-essential-health-services-100-million-still-pushed-into-extreme-poverty-because-of-health-expenses. [Accessed 17th September 2023].

YANG, Y. Y., HE, H. G., LEE, S. Y., HOLROYD, E., SHOREY, S. & KOH, S. S. L. 2017. Perceptions of Parents With Preterm Infants Hospitalized in Singaporean Neonatal Intensive Care Unit. *The Journal of perinatal & neonatal nursing,* 31(3)**,** 263-273.

YU, X., ZHANG, J. & YUAN, L. 2020. Chinese Parents' Lived Experiences of having Preterm Infants in NICU: A Qualitative Study. *Journal of pediatric nursing,* 50**,** e48-e54.

Chapter 2

Exploring the assessment of parental stress within the neonatal environment: A qualitative study of Psychologists'' views

Prepared in accordance with the author requirements for Journal for Perinatology.

https://www.nature.com/jp/authors-and-referees/guide-to-authors

Plain language summary

Title

Exploring the assessment of parental stress within the neonatal environment: A qualitative study of Psychologists' views.

Background

Becoming a parent is a transition which can bring challenges and change. Further challenges can make this transition more difficult, with one of these being a baby's admission to the Neonatal Intensive Care Unit (NICU). Having a baby who requires care within NICU is a significant source of stress for parents. It requires them to adapt to a new environment and alters their experience of becoming a parent. Professionals need to understand how parents manage within this environment to be able to provide support and improve outcomes for both parents and babies. There are existing measures that aim to measure parental stress within NICU, however it has been suggested by professionals working in the field that these measures are not widely used in clinical practice in the UK. However, no formal research has examined clinicians' views/experiences of using these measures in a clinical setting.

Aims

The aims of this project were to explore NICU psychologists' views of the strengths and limitations of existing parental stress measures and, if relevant, to identify what factors would be useful to include in a new measure.

Methods

Practitioner Psychologists who were registered with The Health and Care Professions Council (HCPC) and work in NICUs across the UK were invited to take part in the study. They were recruited via three different professional groups that exist for psychologists working in NICU. 12 HCPC-registered psychologists participated in the study. Initially, an online self-reported questionnaire was completed which gathered information on their current practice and use of measures as well as demographic information and informed consent. Next, a one-to-one semi-structured interview took place via Microsoft Teams. Framework Analysis was conducted to identify themes in the interview data.

Main findings

Three themes were identified; 'Current practice', 'existing tools' and 'is it needed?' Findings indicated that currently there is no standard way for assessing parental stress and clinical assessment appears to be key within NICU. Bespoke or other measures are used occasionally, but this appears to be case specific. There was limited experience of the current existing measures for parental stress and the strengths and weaknesses of the measures were identified. Clinicians

differed in their views of what would be helpful to include in a new measure and there were conflicting ideas about whether it was needed.

Conclusion

This study was the first to examine clinicians' view of existing measures and how parental stress is currently assessed. It highlighted the strengths and weaknesses of the current measures as well as recognising the barriers to implementing measures in NICU. It highlighted that clinicians felt measures were important for service development, but less so for parents. Services therefore may need to consider alternative ways to evidence the work they do in NICU. There were conflicting results regarding the development of a new measure, however all clinicians indicated that a measure would need to encapsulate the entire NICU experience and aid assessment.

Abstract

Objective

Having a baby who requires care within The Neonatal Intensive Care Unit (NICU) is a significant source of stress for parents. Measures exist that aim to assess parental stress within NICU, however these are not widely used in clinical practice in the UK. The study aimed to explore how NICU psychologists assess parental stress and their views of existing measures.

Methods

Semi-structured interviews were conducted with 12 HCPC-registered psychologists who work in NICUs across the UK. Framework Analysis was conducted to identify themes from the interview data.

Result

Three overarching themes and 11 sub-themes were identified. Results indicated that currently there is no standardised way for assessing parental stress and there is limited use of existing measures. Differing views on a new measure were also found.

Conclusion

The study highlighted the strengths and weaknesses of the current measure. Conflicting results regarding the development of a new measure were found, however all clinicians indicated that a measure would need to encapsulate the entire NICU experience and aid assessment.

Introduction

Stress

In the modern world, everyone has experienced 'stress' at some point in their life, it is a widespread and universal phenomenon. Stress can lead to a feeling of fear and anxiety and depending on the circumstance, the fear response may lead to activation of the body's flight or fight response. However, the definition of stress can often be ambiguous and difficult to define as various theoretical context exist to conceptualise it. Over the years, different conceptualisations of stress have been proposed, with stress being viewed as, a response, a stimulus, and a transaction.

Stress was initially viewed as a purely physiological response (Selye (1956) and its function was to restore the body to homeostasis. However, if stress is viewed as a purely physiological phenomenon, it ignores factors such as individual differences or the role of cognitions. Following this, Holmes and Rahe (1967), inspired by their interest in what happens when a person experiences a change in life circumstances, proposed a stimulus-based theory of stress. They viewed stress as a stimulus, life-event or circumstances that results in a physiological and or psychological reaction that demands response, adjustment, or adaptation by an individual. This theory assumed that all change was stressful and that different life changes demanded the same level of adjustment across individuals. This theory was expanded to introduce the concept of an individuals' interpretation, suggesting that a change or life event could be viewed positively or negatively by an individual based on cognitive and emotional factors. However, this theory ignored the wider context and individual differences such as prior learning, personality, life experience and support networks.

In an attempt to explain stress as more of a dynamic process, Lazarus and Folkman (1984) developed the transactional theory of stress and coping. This theory suggests that stress is a product of a transaction between a person (including multiple systems: cognitive, physiological, affective, psychological, neurological) and his or her complex environment. This definition expanded how stress was viewed and acknowledged the wider psychological and social contexts. The critical part of this theory is the emphasis that is placed upon the appraisal the individual makes of the demanding or threatening event, known at the stressor, and it is the appraisal of these stressors that influences the reaction, otherwise known as the stress response. It proposed that this appraisal takes place in two stages; primary and secondary appraisal. The primary appraisal involves a judgement about the potential harm or threat to wellbeing that the stressor has, with the secondary appraisal focusing on the judgement or options available to the individual to cope or manage that stressor and how effective option will be. If a person appraises an event as harmful and believes that the demands imposed by the event exceed the available resources to

manage or adapt to it, the person will subjectively experience a state of stress. In contrast, an individual does not appraise the same event as harmful or threatening, they are unlikely to experience stress. According to this definition, environmental events trigger stress reactions by the way they are interpreted and the meanings they are assigned by the individual.

Becoming a parent in the Neonatal Intensive Care Unit (NICU)

Becoming a parent is one of the most challenging developmental transitions in the family life cycle. It can increase stress, impact on quality of life and requires a period of change and re-adjustment to roles, relationships, and lifestyle (Martins, 2019). Certain situations during the perinatal period can further challenge this transition, with one such being an infant's admission to NICU. It is widely accepted that having an infant requiring care in a NICU is a significant source of stress for parents. Parents need to adjust to the medically-focused environment of the NICU and navigate a reality which differs to their expectations of early parenthood (Bry and Wigert, 2019, Sabnis et al., 2019). Parents experience stress over their infant's health, while also confronting complex and contradictory emotions that arise from having an infant who requires medical attention (Arnold et al., 2013). Professionals are involved in providing care and treatment to their infant which can result in parents feeling disempowered and insignificant in their infant's care (Ionio et al., 2019). Parents may also have other life obligations outside of the hospital which they have to maintain while also trying to care for their sick infant (Grunberg et al., 2021).

Alongside these different stressors, there are numerous factors associated with the stress response of parents within the NICU, including parental age, with older mothers reporting higher levels of stress than young mothers (Dudek-Shriber, 2004), partner relationship quality, parental coping strategies and available resources and support (Pinelli et al., 2008). How this stress manifests is also thought to differ between mothers and fathers (Ionio et al., 2019) with mothers reporting significantly higher levels of stress than fathers in relation to the alteration in the parental role (Miles et al., 1992).

NICU parents report elevated emotional distress compared with parents of healthy full-term babies, with general scales measuring anxiety, depression and post-traumatic stress disorder (PTSD) showing a substantial percentage of NICU parents exceeding clinical cut-off scores (Hynan et al., 2013). However, these measures fail to highlight nuanced issues relating to the specifics of the NICU, thus potentially impacting on parental support and effective intervention strategies being offered (Reid et al., 2007).

The role of psychology in the NICU

Given the nature of an admission to the NICU and the array of negative psychological consequences that may occur for parents, the neonate and the parent-baby relationship (Grunberg

et al., 2019) it is vital that psychological provision is provided to families within the NICU setting. The Ockenden report (2022) highlighted that 'care and consideration of the mental health and wellbeing of mothers, their partners and the family as a whole must be integral to all aspects of maternity service provision (p175).

Clinical psychologists and other accredited psychological professionals, working within NICU have a specialist interest in neonatology and provide evidence-based psychological assessment and interventions to parents, infants and staff in the NICU. Psychologists use several therapeutic models to support parent's mental health needs and undertake peri-trauma work (British Association of Perinatal Medicine (BAPM), 2022) as well as providing interventions for a range of specific issues that arise with being in a NICU, such as adjustment and transition, end of life care and complex decision making. They may also provide post-discharge follow up with families to help with the transition home period and the psychological processing of their infant's NICU stay, development outcomes or diagnosis. Psychologists within this setting may also assess and refer to more specialist perinatal mental health services/ specialist services if required.

As well as supporting parents within this setting, psychologists are trained in attachment and developmental theory which enables them to consider the infant-parent relationship and the bonding process. They are therefore able to support the development of the attachment relationship between parents and the infant with the aim of improving infant mental health and longer-term outcomes for the neonate.

Psychologists not only work on an individual level with infants and families in the NICU but also at a system level. They work as part of the wider multidisciplinary team, providing consultation on complex or distressing clinical situations as well as offering supervision to other professionals within the NICU delivering psychological based interventions. They may also provide de-briefs and reflective practice spaces and provide training and teaching to the NICU team. With psychology embedded within the NICU, it also allows the development and delivery of NICUs to be more psychologically informed environments.

Measuring parental stress in the NICU

Qualified psychologists working in Maternity and Neonatal services in Scotland must complete seven NHS Education Scotland modules as well as a two day training course specific to Maternity and Neonatal Psychology, with a large focus of this being on parental stress in the NICU. An equivalent of this does not currently exist in England and Wales at present.

One possible way to assess and consider patental stress within this environment is through the use of standarised outcome measures. The Parental Stressor Scale: Neonatal Intensive Care Unit (PSS-NICU) (Miles et al., 1993) was designed to measure parents' perception of stressors, both

physical and psychosocial, within the neonatal environment. It was designed based on Magnussen's Stress Theory (1982) where 'stress is viewed as an individual's reaction to demands that approach or exceed limits of coping resources'(Miles et al., 1993, p148).The scale was adapted from a paediatric version and was modified to focus on the physical elements and interpersonal transactions in NICU. The PSS: NICU contains 46 items that are grouped together into four dimensions: sights and sounds; the infant's appearance; staff behaviours and communication; and parental role and relationship with infant. One additional item asks parents to rate their overall stress of the NICU experience. Parents are asked to rate their experience using a five-point Likert scale (1- Not at all stressful to 5- Extremely stressful) or they may rate the item as non-applicable. The scale has been shown to have good reliability and validity with a UK population (Franck et al., 2005). Similarly, Reid et al. (2007) developed the Neonatal Unit Parental Stress (NUPS) Scale. This scale was developed following an evaluation study of the PSS-NICU (Reid and Bramwell, 2003) where they identified a need to explore a wider range of sources of stress for parents including social/practical strains, problems with role transitions, and environmental stressors. As a result, they developed an expanded scale. Reid et al. (2007) reported good reliability and construct validity and considered the content of the scale to be considerably different from the PSS-NICU; however, there is a lack of research on the use of the NUPS following its development. Additionally, other measures may be used within this environment to measure stress, including the Impact of Event Scale- Revised (IES-R)(Weiss, 2007) which is a 22-item self-reported measure that focuses on subjective distress caused by a traumatic event. This measure is relevant within NICU context, especially in the context of traumatic births, however items are not specifically focused on the NICU, which is a limitation with using this tool.

Current clinical context

Despite scales existing that focus on measuring parents' stress in NICU, the National Neonatal/Paediatric Intensive Care Psychology Special Interest Group (NICU/PICU SIG) reports there is not widespread use of either the PSS-NICU (Miles et al., 1993) or NUPS (Reid et al., 2007) in a clinical context in the UK (NICU/PICU SIG, 2021 personal communication). The NICU/PICU SIG have suggested that this is likely due to the language used, the perceived assumptions that some questions make and difficulties with using these measures for different clinical involvements, for example in end-of-life care.

As this information was anecdotal and no previous empirical research had been conducted examining clinicians' views/ experiences of using these parental stress measures in a clinical setting, the current study aimed to understand why these measures were not being used routinely. It also aimed to understand how parental stress is assessed within NICU if these measures are not

routinely administered, and how these measures are experienced by clinicians. By developing an understanding of clinicians' views, it is hoped that this will enhance psychological assessment of parental stress within the NICU setting.

Aims

This aims of this project were to explore NICU psychologists' views of the strengths and limitations of currently available parental stress measures and, if indicated, to identify which factors would be useful to include if a new tool was to be developed in future.

Research Questions

1. How are NICU psychologists currently assessing parental stress in the neonatal environment?
2. What are NICU psychologists' experiences of using standardised measures for this purpose and what are their views on the strengths and limitations of those measures?
3. What factors do NICU psychologists think would be useful to include in an ideal measure examining parental stress in the neonatal environment?

Methods

This study is reported in accordance with The Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014) (Appendix 2.1, p97)

Design

This study employed a mixed-methods design.

Ethical approval

The study was approved by the University of Glasgow Medical, Veterinary and Life Sciences ethics committee (Appendix 2.2, p100). As this study recruited participants from two Scottish National Service Scotland (NSS) bodies, rather than specific health boards, NHS National Research Scotland (NRS) requested that the study was also submitted via IRAS for a generic management review. NHS management approval was granted (Appendix 2.3, p101) on behalf of NSS.

All participants provided informed written and verbal consent. Verbal consent was audio recorded before each interview commenced. Relevant data protection regulations were followed for data collection and storage.

Participants

Eligible participants were HCPC-registered practitioner psychologists working within Neonatal units across the UK. All participants were required to have experience working clinically in a neonatal unit (for any duration), offering assessment and psychological intervention to parents who have/have had a baby in the NICU.

Participants were excluded if their clinical responsibilities were within paediatric intensive care services only. Participants were also excluded if they were employed in other psychological roles which are not eligible for HCPC-registration.

Recruitment

Participants were recruited via the NICU/PICU SIG (a non-NHS UK-wide organisation), Maternity and Neonatal Psychological Interventions (MNPI) Forum and the Perinatal Mental Health Network Scotland (PMHS) Clinical Forum (both part of NHS NSS). This involved the lead researcher (RG) attending one of the scheduled meetings for each of the above-mentioned groups and discussing the research. The study information sheet (Appendix 2.4, p102), privacy notice (Appendix 2.5, p103) and reply slip (Appendix 2.6, p104) were then circulated to all group members via either an email group or social media. Interested participants were asked to return the reply slip. All participants were entered into a draw to win a £20 gift voucher for their participation.

Materials

A pre-interview questionnaire (Appendix 2.7, p105) was created using Microsoft Office Forms and was sent to each participant prior to interview. A detailed consent form (Appendix 2.8, p106) was incorporated at the start of the questionnaire.

The interview schedule (Appendix 2.9, p107) was created and informed by the research questions and the relevant background literature. An initial draft interview schedule was created in consultation with a Consultant Clinical Psychologist who works within an MNPI service. This draft was further refined during supervision. Given the anecdotal evidence that current parental stress measure were not being used (NICU/PICU SIG, 2021 personal communication), it was also agreed that the PSS-NICU (Miles et al., 1993) and NUPS (Reid et al., 2007) should be shown to participants during the interview process in order to prompt feedback regarding the strengths and limitations of these measures.

The interview were semi-structured and constructed in a liner way that allowed participants to initially consider the assessment process in the NICU, before considering the specific assessment of parental stress. This was then followed with questions relating to the use of existing parental stress measures before concluding with what would be useful for current practice when assessing

parental stress in when the NICU. Given the structured nature of Framework Analysis it was agreed that it would be useful to structure the interviews in this way as this would allow an initial deductive approach to be taken when creating the framework for analysis to answer the specific research questions. Although the interviews were semi-structured, with set questions, as the interview process progressed with each participant, the semi-structured approach evolved, whereby more prompts and exploratory questions were used which allowed each participant to answer the research questions as well as explore their own unique experiences working within the NICU.

Procedure

On receipt of the reply slip, each participant was sent the pre-interview questionnaire via email. Following completion, a suitable time and date was arranged to meet for interview. Interviews took place between January and May 2023. Participants took part in interviews via Microsoft Teams. Interviews were conducted in a private, confidential space with no others present. The information gathered within the questionnaire was reviewed prior to the interview and was used to guide each interview alongside the interview schedule. Clarifying questions and probes were also used to elicit participants' in-depth views and to encourage participants to expand on their answers. The PSS-NICU (Miles et al., 1993) was also shared on screen during interviews. Debriefing space was left at the end of each interview to discuss any concerns, however no participant used this.

All interviews were audio-recorded using two password protected handheld Dictaphones before being transcribed verbatim following each interview.

Data Analysis

The demographic data were summarised to characterise the sample. Framework Analysis (Ritchie and Spencer, 2002) was used to analyse the qualitative data. Framework Analysis is a type of thematic analysis where the overall objective is to identify, describe and interpret key patterns and themes within and across cases in the phenomenon of interest (Goldsmith, 2021). It was chosen for the current study as it enables themes to be identified both inductively from the data itself and deductively from the research question and existing literature (Ritchie and Spencer, 2002) meaning that it would allow for specific issues to be explored while allowing aspects of the participant's experiences to be discovered. It is also most frequently used for analysing data from semi-structured interviews (Gale et al., 2013).

Data analysis followed the five-stage model of Framework Analysis (Ritchie and Spencer, 2002) shown in Figure 2.1.

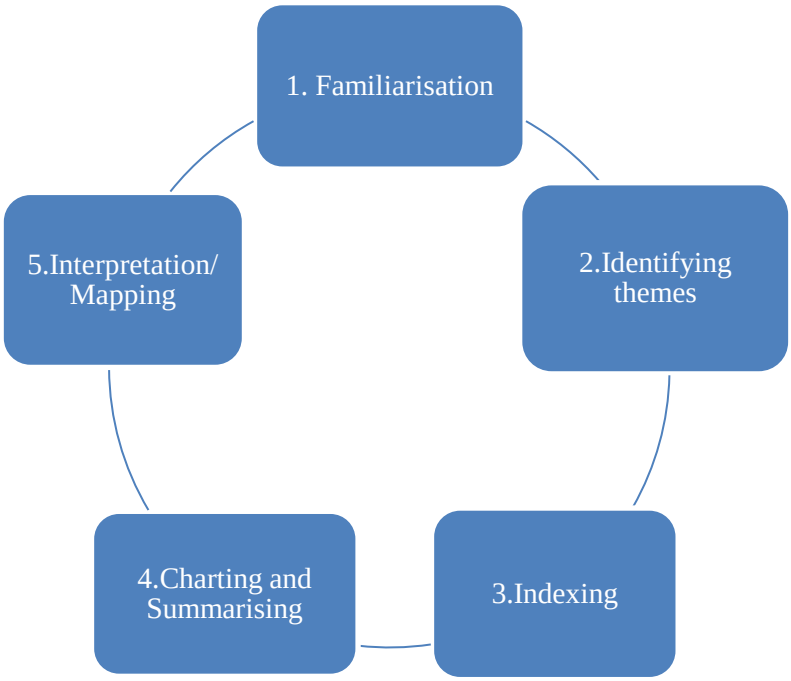

Figure 2.1 - Phrases of Framework Analysis (Ritchie and Spencer, 2002)

The initial stage involved the lead researcher familiarising themselves with the data through re-listening to the interviews and reading the transcripts; this allowed the researcher to have an intimate knowledge of the data before beginning to identify themes and sub-themes that were developing. Themes were developed inductively and deductively which then allowed a thematic framework to be constructed. The transcripts were then indexed according to this framework before the data was summarised and charted on Microsoft Excel according to themes. As this approach is dynamic, it allowed for changes, additions, and amendments to occur throughout the analytical process (Srivastava and Thomson, 2009). The final stage involved mapping and interpreting the data, analysing the charted data, reviewing field research log and searching for patterns and connections to establish themes and an explanation for the research question.

Indexing was carried out by the lead researcher. The two other members of the research team (BC & MF) reviewed one of the annotated interview transcripts and provided reflections on initial themes which were then incorporated into the framework. The charting matrix was also reviewed by BF before the interpretation stage began.

Sample size

There have been considerable differences noted in sample size for qualitative studies utilising Framework Analysis, with studies ranging from eight participants (Gibbs et al., 2021) to 77 participants (Parkinson et al., 2016) with limited justification for sample size noted.

The concept of ‘information power’ (Malterud et al., 2016) was used to help guide an adequate sample size for the current study. Information power indicates that the more information the

sample holds, relevant to the study topic, then the lower number of participants are needed (Malterud et al., 2016). Sufficient information power depends on the aim of the study, sample specificity, use of established theory, quality of dialogue and analysis strategy.

As the current study had a narrow focus, with participants holding highly specific knowledge relevant to the aims, a relatively low sample size was considered adequate. A previous study examining neonatal nurses' perceptions of their roles used eight participants for Framework Analysis (Gibbs et al., 2021). However, as the current study was exploratory in nature with limited theoretical background, a larger sample size was desirable. Considering this in line with the points noted above, this study aimed to recruit 12-15 participants to ensure codes and themes could be sufficiently identified.

Reflexivity

Interviews were conducted and analysed by the lead researcher RG. RG is a white, female, Trainee Clinical Psychologist who at the time of data collection was on placement within a Maternity and Neonatal Psychological Intervention (MNPI) Service within the West of Scotland. This placement not only shaped the lead researcher's knowledge of MNPI services but also contributed to certain assumptions and biases pertaining to parental stress and the role of psychology within the NICU that the researcher holds. Participants were aware of the researcher's job through the recruitment process.

It is important to reflect on one's assumptions, expectations, and identity (both professional and personally) and how these interact and influence the data (Olmos-Vega et al., 2023). The lead researcher took a 'critical realist' stance during the study, which suggests that whilst there is an objective reality, this is mediated by socio-cultural meanings and the researchers' and participants' interpretations. Instead of viewing the lead researcher's knowledge, training and interests as impeding the analysis, it is acknowledged that these are fundamental to developing a subjective interpretation and in the development themes.

A reflective journal (see sample extract in Appendix 2.10, p108) was kept by RG during the data collection, analysis and write-up phase. The dual role of 'researcher' and 'trainee' was a topic of clinical and research supervision throughout the project and reflective discussions were supported by the supervision team which allowed for greater reflexivity during the project. Other members of the research team reviewed transcripts and coding to aid reflectivity.

Results

Participant characteristics

A total of 150 people were invited to participate. Initially 15 people responded; however, two participants were not registered with the HCPC and therefore were not eligible to participate, one individual who noted an interest in participating did not complete and return the reply slip.

In total 12 participants were interviewed- 11 were female, and the age range of the sample was between 25-54 years. All participants were white. Nine were based in NHS Scotland, with the remaining three from NHS England. The length of time that participants had worked in a neonatal setting ranged from one year to 23 years, with the majority (*n*=7) having worked in this setting for under two years. Four of the participants held Consultant Clinical Psychologist positions.

Only one participant reported using the PSS-NICU (Miles et al., 1993) in current practice. Six participants reported using the CORE-10 (Barkham et al., 2013), five reported using the IES-R (Weiss, 2007) and four stated they were not using any outcome measures to measure parental stress. All participants said that they used clinical interview and information from the wider Multi-Disciplinary Team (MDT) to measure parental stress.

Development of the framework

An initial framework consisting of nine main themes was created following the familiarisation stage, with subthemes added as they were identified. This framework was reviewed and refined and was condensed to 8 main themes (Appendix 2.11, p109). These themes were used to index and structure the data during the charting process.

The framework was further refined during the mapping and interpretation stage to the final three themes: 'current practice', 'the existing tools' and 'is it needed?', with 11 subthemes, two of which were broken down to a further three subthemes each, shown in Figure 2.2**Error! Reference source not found.**. Some of the subthemes were interlinked which is depicted by the dotted lines in Figure 2.2.

Each subtheme is described below, illustrated by extracts from the transcripts. These quotes are *ad verbatim* and '…' indicates that some text has been removed.

Figure 2.2- Map of final framework used for analysis.

Current practice

Stress is expected.

"*There is a bit of an expectation that stress is a kind of normal reaction to what they are experiencing"* (ID564).

Throughout the interviews it was apparent that there was a shared understanding between all participants that parental stress existed within the unit and that it was a normal and expected response to parents' circumstances.

Participants recognised that stress arose from a whole range of sources and it was multifaceted. Several participants noted that parental stress was intrinsically linked to their baby's health status*: "You know their stress is so linked to the health of their baby. I doubt they are ever going to be jumping for joy and I think that is what we can expect"* (ID102). Whereas others referenced the more practical issues impacting on parental stress; *"Parental stress in a NICU is often massively informed by their environmental factors, … other kind of childcare responsibilities … financial difficulties … physically being able to get there and back."* (ID236).

Interestingly, everyone raised the importance of the pregnancy journey when considering stress, with one participant discussing the longevity of the stress that parents can experience; *"Often these families have multiple stressors before they even become pregnant. The pregnancy results in stress. They are then subjected to a hugely stressful admission and then like a future that is also full of potential stress as well"* (ID414).

No standardised/formal way.

Although there was recognition between all participants that stress existed, there did not appear to be a 'standardised/formal' way for measuring stress in practice.

More than half of participants stated that they had no knowledge of either of the existing measures for parental stress; *"No knowledge of measures. I have no idea to be honest"*. (ID542). The remaining participants reported to having knowledge of the PSS-NICU, with the majority stating they had considered using this tool when they first joined their MNPI service; *"when we first set up the service, we were thinking about … the parental stressor scale and we had a bonding questionnaire. I think these were the two main ones we were going to use"* (ID267).

However, as reported above, only one participant stated they were using it currently within clinical practice and even then, they advised that this was rare. *"The neonatal version of the parental stress scale but I very rarely use that clinically"* (ID414).

Only one participant reported to have knowledge of the NUPS; "*I have heard of that … I just never call it NUPS."* (ID236). However, despite this knowledge, they advised that they were not using it in their current practice due to the practicalities around access; *"Partly because [of] funding issues … some of them cost money and we don't have a base, so we don't have anywhere to store them"* (ID236) which ties into the subtheme of 'practical barriers'.

Bespoke or other ways to measure stress.

Participants discussed other ways that they were assessing parental stress within the unit. Many reported to be using a simple Likert scale: *"Often, I would ask families on a scale of one to ten … where their coping is at … and where their stress is at"* (ID542), while a small number of participants stated they were using bespoke tools; *"The only other measure I've used is called the Neo wheel."* (ID362). However, the participants using the Neo Wheel were clear that this was not an objective measure of parental stress and was a tool that aided the assessment process; *"It's not measuring something, it's not like the parental stress scale … measuring like a kind of central core psychological construct. It does the opposite, it thinks about breadth … it's measuring, it's the things that people care about when their babies are in the hospital."* (ID414).

As reported above, half of the participants stated they were using the CORE-10 for measuring overall 'distress'; *"I'll use the CORE-10 mainly … it's a helpful way of demonstrating any sort of change (*ID564). However, this use also appeared to be inconsistent among participants, with one noting disparity within their service; *"The CORE-10 because that fits clinically with our practice, but I don't think we are consistent with that between the clinicians"* (ID267).

Two participants highlighted mandatory use of the CORE-10 within their service; "*So currently we have to do the CORE-10"* (ID236), however this participant also stated that it wasn't always clinically appropriate; *"I find sometimes, it doesn't really fit our population that well. It can feel quite abrasive"* (ID236).

Clinical assessment is key.

Although there did not appear to be a 'standardised/formal' way of measuring parental stress, there was a consensus across all participants that clinical assessment was key to measuring stress; *"I basically think it is through clinical interview is how we assess stress, especially at that first point".* (ID159) With another voicing, "*it is actually only through having that assessment of an individual family that you are going to get a true understanding".* (ID267).

Some participants did recognise that measures could aid the assessment process, but still felt that these tools needed to be accompanied by clinical assessment; *"We don't expect measures to do everything but that's where the clinical discussion is still very vital"* (ID586).

All participants mentioned how their clinical assessments tended to focus on the specific pregnancy/neonatal journey of the parents; "*I do an assessment that usually gives people the chance to talk about their whole kind of pregnancy journey and about their birth"* (ID362). However, the majority recognised this journey would differ for each family and there was a need to offer an individualised approach*; "Tailoring the assessment to that individual person"* (ID159).

Existing tools

Experience of using outcome measures.

As most participants noted that they were not using existing parental stress measures, it was difficult to ascertain their experience of using these specific tools. After seeing the PSS-NICU, a couple of participants did voice their concerns about this measure *"putting words in people's mouths"* (ID102) and *"highlighting somethings for families that they haven't come up against*" (ID564) whereas one participant thought it *"would be really helpful"* (ID297).

Of the participants who discussed using any outcome measure with this population there were varied opinions. This appeared partially influenced by their own beliefs regarding the use of

outcome measures with one noting that outcome measures in general were *"not my style"* (ID159). Interestingly, the participant who noted the PSS-NICU to look helpful stated that they thought outcome measures in general were useful; *"I think they are incredibly useful."* (ID297).

One participant reported never having used any measures within the NICU but acknowledged using *"Parenting stress indexes in other settings, in community paediatrics and acute paediatrics and in CAMHS*" (ID313). This links into the theme of the 'NICU as a unique experience' as it highlights that for this participant there is something about the NICU environment that influences their decision not to use measures.

Strengths

Normalising distress

Some participants felt that using the PSS-NICU, would help normalise the stress that parents were experiencing; **"***It would be helpful in terms of normalising those as things that people struggle with"* (ID297) and could be a "*helpful prompt … to actually talk about their experience"* (ID297). One participant discussed how it could be a useful reminder to clinicians that not everyone has experience of this setting before; *"although it is actually normal for us to see these tubes and babies in these closed incubators, actually that is not normal for the majority of the population"* (ID102) and could normalise thinking about other factors besides just the physical health status of baby.

This theme was interlinked with the subtheme 'clinical assessment is key' as although participants highlighted normalising distress as a potential strength, most discussed how this could be done via the clinical assessment process; *"many of those come up in the general discourse of the assessment"* (ID586) with participants highlighting that it felt more comfortable to embed the questions within the assessment; *"we embed the questions within our assessment, it feels much better in a neonatal population"* (ID542).

Factors are relevant.

Most of the participants did discuss that the relevant factors were covered within the PSS-NICU; *"All of those factors are really relevant and really key things that I would expect to cause some distress in the NICU"* (ID159). Some participants saw this as a benefit and felt that it could help to reduce *"the sense of shame, stigma and isolation that comes with the NICU admission"* (ID586).

Proving worth

There was agreement across all participants that outcome measures in general were important for *"proving worth"* (ID542). Participants recognised that they were important in terms of securing funding for services, auditing, and service development with one participant stating the use of

outcome measures is a fundamental part of the clinical psychologist role; *"we usually do use outcome measures as psychologists that's part of our training, to measure outcome robustly and as a service to be able quantify what we do"* (ID313). Coincidentally, this is the same participant reported above who used outcome measures within other clinical specialities but not within their current role, again potentially highlighting the uniqueness of this environment.

Some participants discussed how the PSS-NICU could help to identify the stress within the unit and the subsequent requirement for psychological support within the unit; "*I think that it is good for justifying why we would have a psychology service because you are identifying the level of distress*" (ID267). Others noted how it could be used to measure changes in stress over time; "*It is also good for outcomes so we can measure whether stress/distress is going down, and if it is rising what is contributing to that"* (ID587).

Most participants did comment on how they felt that the use of measures would be more helpful from a service point of view, rather than for the families themselves; *"It is more helpful for us as a service to have that data than necessarily the family themselves to have those questionnaires delivered"* (ID564). However, a couple of participants did think that it might be helpful for families to track change, especially in cases where parents might feel 'stuck'; "*For them to notice objectively that things have shifted, even though subjectively they might think they are in the same place."* (ID313).

Limitations

Practical barriers

Participants discussed several practical barriers to using the PSS-NICU including timings of completing the tool with families; *"I think the last thing they need as they fill in all the discharge paperwork from the hospital is for me to be saying, 'oh and can you fill in a wee questionnaire'".* (ID267)

Others discussed how parents can be discharged before there is the opportunity to complete a follow up and therefore how 'meaningful' is the first score; *"If it was the case where we were giving it out first and last appointment. There's an issue with that because sometimes families are discharged before you even see them, so you might not get a post measure. How would I interpret that?"* (ID313).

One participant who works predominantly with families where prognosis is poor or at end-of-life care stated; "*There is something for me about when you would give the post measure and especially because sadly we have very poorly children and babies who don't survive so when would you give that second measure and then is it worth it?"* (ID159).

Others touched on the language used within the PSS-NICU as being negatively skewed; "*I did find the language quite negative and quite anxiety provoking"* (ID313). The participant who noted using the PSS-NICU did discuss the *"cultural constraints"* of the language within the tool as it was developed in America noting; "*And if the words don't quite fit for you then it feels like maybe it is ships passing in the night"* (ID414).

The physical tool

A common barrier that many of the participants discussed was the actual physical paper measure; *"Here's two pages of really difficult things you have been experiencing, could you tick them all please"* (ID586) and how difficult it might feel for parents to have it *"written down on paper"* (ID313). One participant highlighted how mis-attuned a questionnaire felt within the NICU; "*If you think about the practical ramifications of thrusting a questionnaire… in front of an exhausted mother who is trying to express her milk … then you are not attuned"* (ID102). Another participant noted that *"you're taking away from the situation by being like 'let's do a measure'"* (ID362). Some participants noted that offering some form of 'score' for their distress also felt inappropriate; *"I think there is something about scoring them that doesn't feel quite right in that setting"* (ID267) and that this felt like they were *"almost pathologising distress by quantifying it"* (ID587) which interlinks with the subtheme 'stress is expected'.

However, one participant felt that the paper tool was a strength and helped to normalise parents' experience; "*If it's on a form, it must be quite normal"* (ID236).

Lack of sensitivity

Several participants felt that as stress was expected, participants would inevitably score highly on this measure; *"If you are a parent in the neonatal unit and you fill in the parental stress scale, chances are if you are feeling stressed you are going to be scoring… like I am going to be scoring really stressed out on all these questions"* (ID414) which then raised the question of the validity of this score for these participants; *"I would imagine that parents would say they were very stressed on all points, so I am not very sure how useful it would be"* (ID587). However, one of the participants did note that this was based on *"their assumptions"* within the NICU and that they might be doing *"parents a disservice*" (ID586) with this view highlighting the influence of participants' beliefs with using measures.

Some participants discussed the cognitive functioning of parents within the NICU; *"I think we know the impact of stress on cognitive functioning" (*ID267) and how this impacts on parents' ability to reflect; "*People's abilities to reliably and accurately access their reflective functioning to be able to make that self-assessment when they are in the acutely distress phase is a struggle"* (ID414) which suggested that if parents aren't able to reflect on their experience, how accurately does their score equate to their level of stress.

Is it needed?

NICU as a unique experience.

The overarching theme that appeared to run throughout each interview was about how unique the NICU experience is; "*I guess just because the experience of the neonatal unit is unique. When parents come here, they've been on so many other journeys…there's just so much going on."* (ID586).

Participants were keen to share that parents hadn't accessed psychological support in the NICU because they had a specific 'problem' but rather they had found themselves being offered support based on the situation in which they found themselves; *"I guess the most important factor is first off acknowledging that parents haven't opted in to coming to the unit because they are coming with a mental health difficulty or something they want support with. They are meeting with us because they are going through a stressful situation, and they are responding to that"* (ID564).

Participants felt that this was relevant when considering a measure for parental stress within the NICU, as most felt unsure that a tool could ever incorporate the unique environment it presents to parents; "*I don't know if outcome measures will ever capture the nuances of the levels of distress they are going through*" (ID102), or that a measure could evidence the work that psychology does within this environment; *"being able to evidence the value of the work that happens on the neonatal units as a preventive approach to psychological intervention is hard"* (ID414).

A new tool?

There were conflicting ideas between participants about whether a measure for parental stress in the NICU was needed.

Some participants felt that the measure already existed; *"That measure you shared [PSS-NICU] feels very specific…yeah I think the measure does cover most of the things that would cause stress on a NICU".* (ID159). Whereas others voiced the need for a new measure; "*I think we need a new one. I would be using one if there was something appropriate but that one there it just doesn't fit for me*" (ID587).

Others voiced concerns about what a measure would add; "*I don't know what would be useful to included that you don't already ask in an interview"* (ID313). One participant *"didn't feel like their job was harder because they weren't using one*" (ID587).

What is the purpose?

All participants were clear that if they were going to use a measure then there would need to be some understanding about the purpose and function of this tool; "*What are we measuring?*

Because usually we are measuring something we can intervene around, and we can change" (ID313).

Some participant voiced concerns about the concept of 'intervention' in the unit, with one stating they were unsure they were delivering a *"standardised intervention around a core psychological construct"* (ID414), thus for them, measuring "change" within this environment felt difficult. Others advised they were unsure what would be classed *"as an improvement? What do we see as a good outcome for these parents?"* (ID102) which links into the sub-theme 'stress is expected' as many discussed that *"what is going to have been most helpful is their babies progress through the unit"* (ID564) and not a specific psychological intervention, and it therefore felt *"disingenuous to use as an outcome measure"* (ID564).

Others discussed using a measure as a 'screen' for identifying parents who required additional support on the unit; *"If every parent filled one in, we might be able to kind of screen and target our approach and referrals … to our team"* (ID564). However, others voiced concerns with a screening approach; "*if you start measuring distress with everyone and distress comes up, but they don't feel that they have any space to look at it, you know what do you do with that?"* (ID102)

Broad and holistic

Although there were differing views of the usefulness and need for a measure within this setting, many participants did advise that if there was to be some form of tool, it would need to be *"broad brush"* (ID267) to encapsulate the whole NICU experience. Participants were keen for a tool to be able to *"understand the breadth of the stressors"* (ID586) whilst also supporting their work; *"To highlight areas of difficulty, so that we can see what supportive interventions map onto that, and we can then facilitate".* (ID414).

Participants were not necessarily looking for something to measure change or to provide a 'score' for stress; *"It's going to tell you a number that means very much less than what you can see with your eyes."* (ID 414) but rather to facilitate the assessment process within this environment; "*Like a measure just to make sure that people know they can talk about it"* (ID362).

Many participants discussed the need for something that was short; *"I could see the value of doing it if it was short and sweet and sort of gave you a good sense of where things might be at"* (ID542) with others highlighting how important the language would need to be; "*It would also need to be trauma informed in terms of wording"* (ID587). The participants who reported to be using bespoke measures, like the Neo Wheel, also reported how well the visual element of this tool worked*; "it is incredibly containing both for families and for clinicians, to be able to see all of this stuff in a really contained, visual thing on one page."* (ID414).

Discussion

This study aimed to explore NICU psychologists' views of the strengths and limitations of currently available parental stress measures and to identify which factors would be useful to include in a new tool if indicated. The interviews provided a lot of information which was reduced to three main themes; 'current practice', 'existing tools' and 'is it needed?'.

How are NICU psychologists currently assessing parental stress in the neonatal environment?

The results suggested that in clinical practice, participants were not using existing parental stress measures, instead opting to rely predominantly on clinical assessment. Some participants noted that their assessment was supported by either bespoke or specific mental health diagnosis measures. However, the uses of these appeared to be case-specific with no standardised method for assessing stress reported by clinicians.

The term 'stress' is an umbrella term that represents experiences in which environmental demands outweigh the individual's perceived ability to cope effectively (Cohen et al., 2016). Several participants commented on 'stress' and the construct being assessed, voicing different views on what they defined as 'stress' and the utility of measuring this within the NICU. Crosswell and Lockwood (2020) argue that viewing psychological stress as 'too vague or broad' to measure results in stress often failing to be considered or measured, especially within a research context. They suggest that this is due to there being no clear distinction made between exposure to a stressful event and the response of the individual to that stressor, which they define as crucial, as each are considering a different concept. "Stressors" are discrete events that can be objectively rated as having the potential to alter or disrupt typical psychological functioning, whereas stress responses are the cognitive, emotional, and biological reactions that these stressful events evoke, which inevitably impact on an individual's functioning.

As the role of psychology within the NICU focuses on 'providing psychological interventions that support mental health, family relationships and infant mental health' (National Leads for Psychological Practice (NeoLeap), 2022, pg. 6) it may be suggested that participants view clinical assessment as being better placed to capture an individual's 'stress response', thus allowing psychological intervention to be tailored to specific needs in line with their role within the unit. It appeared that merely identifying specific stressor or offering a score was not deemed beneficial to practice.

What are NICU psychologists' experiences of using standardised measures for this purpose and what are their views on the strengths and limitations of those measures?

Participants reported that they had limited to no experience of using measures within the NICU. They identified using standardised measures within other environments and clinical settings, however most felt that measures were inappropriate within this setting. All participants highlighted how important measures were at being able to evidence practice from a service development stance but felt nevertheless that these still had limited use with parents in this setting.

Outcome measures have been promoted in healthcare over recent years and are integral to services' ability to provide evidence-based, person-centered care founded on transparency and accountability (Department of Health, 2001). Despite the HCPC stating that a core proficiency of a practitioner psychologist is to *'be aware of the role of audit and review in quality management, including quality control, quality assurance and the use of appropriate outcome measures'* (Health and Care Professions Council (HCPC)(2015), pg.12) evidence suggests that there is a disparity between recommendations and clinical practice with the use of outcome measures across the UK for clinicians (Sharples et al., 2017).

A study conducted within Child and Adolescent Mental Health Services (CAMHS) highlighted that despite holding positive attitudes towards outcome measures, clinicians still reported that they did not feel they help to improve overall patient care, resulting in reluctance to use them (Martin et al., 2011). Unsworth et al. (2012) also found that clinicians had fears about incorporating measures into sessions without it feeling intrusive and clinicians tended to trust their 'own experience' rather than scores within their practice. Furthermore, Hatfield and Ogles (2007) found that only 37% of psychologists in the US indicated that they used some form of outcome measures in practice. Practical elements such as cost and time and 'philosophical' stance- such as clinicians' views on their relevance- were reported as barriers to use, which is also evident within the results found here.

Within the present study, some participants noted that there were concerns about how parents would react to the use of these measures, noting this as a barrier to use. Thew et al. (2015) examined service users' views of outcome measures and found that they generally favored them when they were well integrated into sessions by the therapists. Service users did indicate that it could raise unpleasant feelings, but it also provoked their interest and led to helpful discussions. This conflicts with some of the views found here which raises questions over clinicians' own bias and judgement influencing use.

The barriers recognised here raise an important issue within clinical practice where there is emphasis on services to evidence the effectiveness and the cost-efficiency of services. If measures are not being used routinely, it may be difficult for services to evidence this. Clinicians did raise the potential to evidence effectiveness through gathering more qualitative feedback from parents, however there is a lack of literature to support how this could be implemented in practice.

What factors do NICU psychologists think would be useful to include in an ideal measure examining parental stress in the neonatal environment?

There were differing views about what would be useful or helpful to include in a new measure as well as conflicting ideas about whether a new tool needed to be created. As there was no consensus between participants, it is difficult to conclude what an ideal measure would look like within NICU. However, there was an understanding throughout that stress was expected and that to consider this, a measure would have to be broad, support assessment and encapsulate the whole NICU experience.

The Neo wheel was reported to be used by a few participants, this is a prototype of an adapted version of the paediatric wheel (Evans et al., 2021) and identifies eight key areas within NICU that parents report as stressful. Each area is rated on a five-point Likert scale. The Neo wheel was reported to be used alongside clinical assessment as a way of identifying the key areas causing the most stress which in turn informs the support/intervention offered. It was reported as helpful at supplementing the assessment process and covers relevant areas in the NICU, which was noted as being important. However, the wheel does not measure a core construct and is a prototype that is currently in the process of being piloted in a service, therefore further research would be required.

The themes found within this study broadly mirror the research questions and the questions that were asked at the interviews. This was considered an appropriate approach as it was agreed that an initial deductive approach would be the most useful to answer the specific research questions. Initially the themes were created deductively based on the literature, research questions and the interview schedule. However, through the interview process and the use of supervision and reflective logs, inductive themes were identified which were then incorporated into the indexing and charting process. The research was exploring psychologists' experiences of measuring parental stress, therefore by structuring the interviews and results into these three broad themes, it was deemed desirable as it allowed a deeper understanding to the specific questions that were being asked.

Strengths and limitations

One strength is that this study is the first study to examine clinicians' views of using parental stress measures within NICU. This study allowed the views and opinions of clinicians to be explored resulting in recommendations for practice, as well as highlighting further areas of research that are required within the limited evidence base. Further strengths were the methodological rigour and use of reflective practice throughout. The reflective log allowed reflections and reflexivity to be documented at all stages of the research project. It also allowed for the researcher's potential contextual influence to be considered throughout data collection, analysis and interpretation. The involvement of other members of the research team further enriched the analytical process and allowed additional perspectives to be included.

By conducting remote interviews, clinicians from across the UK were able to participate which would not have been feasible if interviews were conducted face-to-face. This provided the opportunity to gain a broader perspective from different NHS boards where practices and policies may vary. The fact that only 15 responses were received from the 150 potential participants may suggest that the final sample were particularly interested in or held strong opinions regarding the assessment of stress within NICU, and this may have influenced the results found here. Also, the exclusion of participants who did not hold HCPC registration but delivered psychological intervention may also have influenced the results as their training and professional framework may have offered different views to what was found here.

One limitation of this study was an assumption by the lead researcher that participants would have knowledge of both the PSS-NICU (Miles et al., 1993) and the NUPS (Reid et al., 2007) prior to interview. The PSS-NICU (Miles et al., 1993) was shared with all participants during their interviews to gain feedback however due to being unable to access the NUPS (Reid et al., 2007), this was not shown to participants and no feedback was acquired in relation to this tool. This means the current study focused predominantly on the PSS-NICU (Miles et al., 1993) when other measures are available. Given the difficulty in accessing this tool and the lack of knowledge amongst clinicians, it could be suggested that these were barriers to using the NUPS (Reid et al., 2007). It might be useful for future research to examine clinicians' views of the NUPS (Reid et al., 2007) as this could highlight different themes that were not found here.

A further limitation is that the current research focused solely on clinicians' views and experiences of assessing for stress in the NICU. Although clinicians' views are vital, further research should examine the views of parents and caregivers to gain the perspective of individuals who access services as well as further insight into what they deem beneficial and require from clinician in NICU.

Clinical Implication.

As highlighted, the concept of 'stress' can be ambiguous and difficult to define, therefore if 'parental stress' is required to be assessed by MNPI services then psychologists need to have a collective understanding regarding the theoretical underpinnings of the construct being assessed. As indicated in the results, merely naming specific stressors and providing a score was not considered helpful, participants struggled to see the utility of doing this and appeared to be looking for more of a transactional-based model of stress where consideration is made to an individuals' interpretation and coping within this environment as this appeared to be where the focus of psychological intervention could take place. It may therefore be useful that specific training for psychologists working within the NICU uses this theoretical framework for discussing and working with parental stress in this environment.

Psychologists recognised that the stressor faced by parents in NICU are different to stressors faced in other environments, and while all participants recognised this, they found it more beneficial within the NICU to embed these questions within their assessment process rather than using a routine outcome measure. This is clinically important as suggests that creating a new tool for measuring parental stress does not appear to be warranted or necessary.

Conclusion

In conclusion, this is the first study to examine how parental stress is currently assessed by clinicians in NICU. It has highlighted that there is no standardised way for measuring stress and how important clinical assessment is. It would also appear that this allowed an individual's current functioning and stress response to be gathered which was deemed more beneficial for psychological intervention than simply a 'score' of stress.

Furthermore, participants did highlight strengths of the PSS-NICU. However, it is not currently being used on clinical practice. The barriers identified included practical barriers, clinician's own views and the physical tool itself. This does raise an important consideration for MNPI services as they will be required to evidence the valuable work they deliver, and services may need to establish an alternative, if outcome measures are deemed unsuitable.

Finally, there were conflicting results regarding the development of a new measure. Participants expected stress within the NICU and discussed needing a measure that would aid the assessment process and cover the relevant areas within NICU. One tool was highlighted as potentially meeting this need, however this is still in development and further research into the utility of this is required.

References

ARNOLD, L., SAWYER, A., RABE, H., ABBOTT, J., GYTE, G., DULEY, L. & AYERS, S. 2013. Parents' first moments with their very preterm babies: a qualitative study. *BMJ Open,* 3**,** 1-7.

BARKHAM, M., BEWICK, B., MULLIN, T., GILBODY, S., CONNELL, J., CAHILL, J., MELLOR-CLARK, J., RICHARDS, D., UNSWORTH, G. & EVANS, C. 2013. The CORE-10: A short measure of psychological distress for routine use in the psychological therapies. *Counselling and Psychotherapy Research,* 13**,** 3-13.

BRITISH ASSOCIATION OF PERINATAL MEDICINE (BAPM). 2022. *Perinatal Psychology* [Online]. http://hubble-live-assets.s3.amazonaws.com/bapm/redactor2_assets/files/882/Perinatal_Psychology_description.pdf. [Accessed 9th September 2023 2023].

BRY, A. & WIGERT, H. 2019. Psychosocial support for parents of extremely preterm infants in neonatal intensive care: a qualitative interview study. *BMC Psychol,* 7**,** 1-12.

COHEN, S., GIANAROS, P. J. & MANUCK, S. B. 2016. A Stage Model of Stress and Disease. *Perspect Psychol Sci,* 11**,** 456-63.

CROSSWELL, A. D. & LOCKWOOD, K. G. 2020. Best practices for stress measurement: How to measure psychological stress in health research. *Health Psychol Open,* 7**,** 2055102920933072.

DEPARTMENT OF HEALTH 2001. Mental health information strategy. Department of Health London.

DUDEK-SHRIBER, L. 2004. Parent stress in the neonatal intensive care unit and the influence of parent and infant characteristics. *Am J Occup Ther,* 58**,** 509-20.

EVANS, D., BARKER-ELLIS, C., CHRISTOPHER, J. & PERKINS, M. 2021. Reinventing the WHEEL: Developing a psychosocial screening tool in a paediatric psychology service. *Clinical Psychology Forum,* 345**,** 64-70.

FRANCK, L. S., COX, S., ALLEN, A. & WINTER, I. 2005. Measuring neonatal intensive care unit-related parental stress. *Journal of Advanced Nursing,* 49**,** 608-615.

GALE, N. K., HEATH, G., CAMERON, E., RASHID, S. & REDWOOD, S. 2013. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol,* 13**,** 1-8.

GIBBS, D., ODEH, N., THERON, M. & HARDING, C. 2021. Level 1 neonatal nursing staff perceptions of their role: A qualitative Framework Analysis study investigating the complex and diverse workload undertaken by nurses in special care baby units. *Journal of Neonatal Nursing,* 27**,** 244-50.

GOLDSMITH, L. 2021. Using Framework Analysis in Applied Qualitative Research. *The Qualitative Report,* 26**,** 2061-76.

GRUNBERG, V. A., GELLER, P. A., BONACQUISTI, A. & PATTERSON, C. A. 2019. NICU infant health severity and family outcomes: a systematic review of assessments and findings in psychosocial research. *J Perinatol,* 39**,** 156-172.

GRUNBERG, V. A., GELLER, P. A., HOFFMAN, C., NJOROGE, W., AHMED, A. & PATTERSON, C. A. 2021. Parental mental health screening in the NICU: a psychosocial team initiative. *J Perinatol,* 42**,** 401-09.

HATFIELD, D. R. & OGLES, B. M. 2007. Why Some Clinicians Use Outcome Measures and Others Do Not. *Administration and Policy in Mental Health and Mental Health Services Research,* 34**,** 283-291.

HEALTH AND CARE PROFESSIONS COUNCIL (HCPC). 2015. *Standards of Proficiency-Practitioner Psychologists* [Online]. https://www.hcpc-uk.org/globalassets/resources/standards/standards-of-proficiency---practitioner-psychologists.pdf. [Accessed 26th June 2023].

HOLMES, T. H. & RAHE, R. H. 1967. The Social Readjustment Rating Scale. *J Psychosom Res,* 11**,** 213-8.

HYNAN, M. T., MOUNTS, K. O. & VANDERBILT, D. L. 2013. Screening parents of high-risk infants for emotional distress: rationale and recommendations. *J Perinatol,* 33**,** 748-53.

IONIO, C., MASCHERONI, E., COLOMBO, C., CASTOLDI, F. & LISTA, G. 2019. Stress and feelings in mothers and fathers in NICU: identifying risk factors for early interventions. *Prim Health Care Res Dev,* 20**,** 1-7.

LAZARUS, R. S. & FOLKMAN, S. 1984. *Stress, appraisal, and coping,* Springer publishing company.

MAGNUSSEN, D. 1982. Situational determinants of stress: An interactional perspective. . *In:* BREZNITZ, L. G. S. (ed.) *Handbook of stress: Theoretical and Clinical aspects.* New York: Free Press.

MALTERUD, K., SIERSMA, V. D. & GUASSORA, A. D. 2016. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qual Health Res,* 26**,** 1753-60.
MARTIN, A.-M., FISHMAN, R., BAXTER, L. & FORD, T. 2011. Practitioners' attitudes towards the use of standardized diagnostic assessment in routine practice: A qualitative study in two Child and Adolescent Mental Health Services. *Clinical Child Psychology and Psychiatry,* 16**,** 407-420.
MARTINS, C. A. 2019. Transition to parenthood: consequences on health and well-being. A qualitative study. *Enfermería Clínica,* 29**,** 225-233.
MILES, M. S., FUNK, S. G. & CARLSON, J. 1993. Parental Stressor Scale: neonatal intensive care unit. *Nurs Res,* 42**,** 148-52.
MILES, M. S., FUNK, S. G. & KASPER, M. A. 1992. The stress response of mothers and fathers of preterm infants. *Res Nurs Health,* 15**,** 261-9.
NATIONAL LEADS FOR PSYCHOLOGICAL PRACTICE (NEOLEAP). 2022. *Psychology staffing on the Neonatal Unit* [Online]. https://acpuk.org.uk/wp-content/uploads/2022/09/Psychology_Staffing_on_the_Neonatal_Unit.pdf. [Accessed 15th June 2023].
O'BRIEN, B. C., HARRIS, I. B., BECKMAN, T. J., REED, D. A. & COOK, D. A. 2014. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med,* 89**,** 1245-51.
OCKENDEN, D. 2022. *Findings, conclusions and essential actions from the independent review of maternity services at the Shrewsbury and Telford Hospital NHS trust. Our final report.* [Online]. https://www.gov.uk/government/publications/final-report-of-the-ockenden-review: House of Commons [Accessed 9th September 2023].
OLMOS-VEGA, F. M., STALMEIJER, R. E., VARPIO, L. & KAHLKE, R. 2023. A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher,* 45**,** 241-251.
PARKINSON, S., EATOUGH, V., HOLMES, J., STAPLEY, E. & MIDGLEY, N. 2016. Framework analysis: a worked example of a study exploring young people's experiences of depression. *Qualitative Research in Psychology,* 13**,** 109-29.
PINELLI, J., SAIGAL, S., BILL WU, Y.-W., CUNNINGHAM, C., DICENSO, A., STEELE, S., AUSTIN, P. & TURNER, S. 2008. Patterns of change in family functioning, resources, coping and parental depression in mothers and fathers of sick newborns over the first year of life. *Journal of Neonatal Nursing,* 14**,** 156-65.
REID, T. & BRAMWELL, R. 2003. Using the Parental Stressor Scale: Nicu with a British sample of mothers of moderate risk preterm infants. *Journal of Reproductive and Infant Psychology,* 21**,** 279-291.
REID, T., BRAMWELL, R., BOOTH, N. & WEINDLING, A. M. 2007. A new stressor scale for parents experiencing neonatal intensive care: the NUPS (Neonatal Unit Parental Stress) scale. *Journal of Reproductive and Infant Psychology,* 25**,** 66-82.
RITCHIE, J. & SPENCER, L. 2002. *Qualitative data analysis for applied policy research. In Analyzing Qualitative Data.,* London, Routledge.
SABNIS, A., FOJO, S., NAYAK, S. S., LOPEZ, E., TARN, D. M. & ZELTZER, L. 2019. Reducing parental trauma and stress in neonatal intensive care: systematic review and meta-analysis of hospital interventions. *J Perinatol,* 39**,** 375-86.
SELYE, H. 1956. *The stress of life,* New York, NY, US, McGraw-Hill.
SHARPLES, E., QIN, C., GOVEAS, V., GONDEK, D., DEIGHTON, J., WOLPERT, M. & EDBROOKE-CHILDS, J. 2017. A qualitative exploration of attitudes towards the use of outcome measures in child and adolescent mental health services. *Clin Child Psychol Psychiatry,* 22**,** 219-228.
SRIVASTAVA, A. & THOMSON, S. B. 2009. Framework Analysis: A Qualitative Methodology for Applied Policy Research. *Journal of Administration and Governance.,* 4**,** 72-9.
THEW, G. R., FOUNTAIN, L. & SALKOVSKIS, P. M. 2015. Service user and clinician perspectives on the use of outcome measures in psychological therapy. *the Cognitive Behaviour Therapist,* 8**,** e23.
UNSWORTH, G., COWIE, H. & GREEN, A. 2012. Therapists' and clients' perceptions of routine outcome measurement in the NHS: A qualitative study. *Counselling and Psychotherapy Research,* 12**,** 71-80.
WEISS, D. S. 2007. The Impact of Event Scale—Revised. *In:* WILSON, J. P. & KEANE, T. M. (eds.) *Assessing psychological trauma and PTSD: A practitioner's handbook.* New York: Guildford Press.

Appendix 1.1

PRISMA 2020 Checklist.

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	8
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	9
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	10 & 11
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	11
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	12
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	11
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	73-75
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	12, 76 & 77
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	12 & 13
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	-
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	-
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	13 & 79
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	-
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	13
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	-
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	17-22 & 24
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	13, 23 & 25
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	-
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	-
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	13
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	-

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	14 & 15
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	-
Study characteristics	17	Cite each included study and present its characteristics.	17-22
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	97
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	-
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	16
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	25-33
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	-
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	-
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	25-33
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	25-33
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	33-35
	23b	Discuss any limitations of the evidence included in the review.	35-36
	23c	Discuss any limitations of the review processes used.	35-36
	23d	Discuss implications of the results for practice, policy, and future research.	37-38
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	11
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	11
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	-
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	-
Competing interests	26	Declare any competing interests of review authors.	-
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	12

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Appendix 1.2

Search strategy for each database.

Ovid MEDLINE(R) ALL <1946 to March 01, 2023>

1 Intensive Care Units, Neonatal/ 17823

2 exp Intensive Care, Neonatal/ 6107

3 (Neonatal or NICU).tw. 238160

4 1 or 2 or 3 243393

5 Parents/79059

6 Caregivers/ 48786

7 (Parent* or Caregiver* or Care giver* or Famil* or Mother* or Father* or Birth Parent*).tw. 1866979

8 5 or 6 or 7 1886390

9 Qualitative Research/ 79687

10 Interview/ 30548

11 ((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire*)) or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant")).tw,kw. or interviews as topic/ or focus groups/ or narration/ or qualitative research/ 504339

12 9 or 10 or 11 534695

13 4 and 8 and 12 2403

14 limit 13 to (english language and yr="2014 - 2023") 1635

Embase <1974 to 2023 March 01>

1 neonatal intensive care unit/ 21010

2 exp newborn intensive care/ 27423

3 (Neonatal or NICU).tw. 322844

4 1 or 2 or 3 334654

5 parent/ 96874

6 caregiver/ 110128

7 (Parent* or Caregiver* or Care giver* or Famil* or Mother* or Father* or Birth Parent*).tw. 2392389

8 5 or 6 or 7 2421134

9 qualitative research/ 112755

10 interview/ 246805

11 (("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire*)).ti,ab. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").tw,kw. or qualitative research/586785

12 9 or 10 or 11 737409

13 4 and 8 and 12 3547

14 limit 13 to (english language and yr="2014 - 2023") 2426

MIDIRS: Maternity and Infant Care (02.03.23)

1 (Neonatal or NICU).tw. 50565

2 (Parent* or Caregiver* or Care giver* or Famil* or Mother* or Father* or Birth Parent*).tw. 89449

3 (("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or questionnaire*)).tw. 7529

4 (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant" or “"Qualitative Research").tw. 11047

5 3 or 4 14834

6 1 and 2 and 5 1109

7 limit 7 to yr="2014 - 2023" 717

EBSCOhost PsycINFO: (02.03.2023)

S1 DE "Neonatal Intensive Care"

S2 TI ("Neonatal or NICU") OR AB ("Neonatal or NICU")

S3 S1 OR S2

S4 DE “Parents”

S5 DE "Parents" OR DE "Adoptive Parents" OR DE "Expectant Parents" OR DE "Fathers" OR DE "Foster Parents" OR DE "Homosexual Parents" OR DE "Mothers" OR DE "Parental Characteristics" OR DE "Single Parents" OR DE "Stepparents" OR DE "Surrogate Parents (Humans)"

S6 DE “Caregivers”

S7 TI ("Parent*" or "Caregiver*" or "Care giver*" or "Famil*" or "Mother*" or "Father*" or "Birth Parent*")) OR AB ("Parent*" or "Caregiver*" or "Care giver*" or "Famil*" or "Mother*" or "Father*" or "Birth Parent*"))

S8 S4 OR S5 OR S6 OR S7

S9 “Qualitative Methods”

S10 TI ((("semi-structured" or "semistructured" or "unstructured" or "informal" or "in-depth" or "face-to-face" or "structured" or "guide") n2 ("interview*" or "discussion*" or "questionnaire*"))) OR AB ((("semi-structured" or "semistructured" or "unstructured" or "informal" or "in-depth" or "face-to-face" or "structured" or "guide") n2 ("interview*" or "discussion*" or "questionnaire*")))

S11 TI ("focus group*" or "qualitative" or "ethnograph*" or "fieldwork" or "field work" or "key informant" or "Qualitative Research") OR AB ("focus group*" or "qualitative" or "ethnograph*" or "fieldwork" or "field work" or "key informant" or "Qualitative Research")

S12 S9 OR S10 OR S11

S13 S3 AND S8 AND S12

S14 S3 AND S8 AND S12 (Limiters - Publication Year: 2014-2023; English).

EBSCOhost CINAHL: (02.03.2023)

S1 (MH "Intensive Care Units, Neonatal")

S2 (MH "Intensive Care, Neonatal")

S3 TI (“Neonatal” or “NICU”) OR AB (“Neonatal or NICU”)

S4 S1 OR S2 OR S3

S5 (MH "Parents")

S6 (MH "Adoptive Parents") OR (MH "Biological Parents") OR (MH "Co-Parents") OR (MH "Fathers") OR (MH "Foster Parents") OR (MH "Mothers") OR (MH "Single Parent") OR (MH "Adolescent Parents")

S7 (MH "Caregivers")

S8 TI ("Parent*" or "Caregiver*" or "Care giver*" or "Famil*" or "Mother*" or "Father*" or "Birth Parent*") OR AB ("Parent*" or "Caregiver*" or "Care giver*" or "Famil*" or "Mother*" or "Father*" or "Birth Parent*")

S9 S5 OR S6 OR S7 OR S8

S10 (MH "Qualitative Studies")

S11 TI ((("semi-structured" or "semistructured" or "unstructured" or "informal" or "in-depth" or "face-to-face" or "structured" or "guide") n2 ("interview*" or "discussion*" or "questionnaire*"))) OR AB ((("semi-structured" or "semistructured" or "unstructured" or "informal" or "in-depth" or "face-to-face" or "structured" or "guide") n2 ("interview*" or "discussion*" or "questionnaire*")))

S12 TI ("focus group*" or "qualitative" or "ethnograph*" or "fieldwork" or "field work" or "key informant" or "Qualitative Research") OR AB ("focus group*" or "qualitative" or "ethnograph*" or "fieldwork" or "field work" or "key informant" or "Qualitative Research")

S13 S10 OR S11 OR S12

S14 S4 AND S9 AND S13

S15 S4 AND S9 AND S13 (Published Date: 20140101-20231231; English Language)

Web of Science

Neonatal or NICU **(Topic) and** "Parent*" or "Caregiver*" or "Care giver*" or "Famil*" or "Mother*" or "Father*" or "Birth Parent*" **(Topic) and** (("semi-structured" or "semistructured" or "unstructured" or "informal" or "in-depth" or "face-to-face" or "structured" or "guide") "near/2" ("interview*" or "discussion*" or "questionnaire*")) OR ("focus group*" or "qualitative" or "ethnograph*" or "fieldwork" or "field work" or "key informant" or “qualitative research”) **(Topic)**

Timespan: 2014-01-01 to 2023-12-31 (Publication Date)

Appendix 1.3

Screening and selection tool

Primary Question- What are parents' experiences of having an infant in the NICU?

Secondary Question- What have parents found helpful/useful/unhelpful when in the NICU?

Reviewer name: **Date:**

Author of study & ID: **Year:**

Title:

Journal:

Include	**Exclude**
Sample	
Parents/Caregivers of an infant in the NICU ☐	Parents/caregivers who do not have an infant in the NICU (E.g., PICU) ☐ Parent/ Caregivers who have lost their infant or where prognosis is poor after admission to the NICU (bereaved parents) ☐ Staff in the NICU ☐
Phenomenon of interest	
Neonatal environment/NICU ☐	Any other hospitalisation (e.g., Paediatric Intensive care) ☐ Non-hospital Environment ☐ Transition/Discharge from NICU ☐
Design	
Qualitative study design ☐	Quantitative study design and Mixed methods. ☐
Evaluation	
Experience or perception of the NICU ☐	Experiences unrelated to the experience of the NICU (e.g., medical interventions/feeding/Discharge/parenting from NICU) ☐ Any intervention provided whilst in NICU ☐

Research Type

Qualitative Studies of any type ☐ (e.g., IPA, TA, Framework Analysis).

Any study design other than Qualitative ☐

Overall decision: Include ☐ Exclude ☐

Notes:

Appendix 1.4

CASP Checklist for Qualitative Research.

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

©CASP this work is licensed under the Creative Commons Attribution – Non-Commercial-Share A like. To view a copy of this license, visit http://creativecommons.org/licenses/by-nc-sa/3.0/ www.casp-uk.net

CASP
Critical Appraisal Skills Programme

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐ Can't Tell ☐ No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐ Can't Tell ☐ No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐ Can't Tell ☐ No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

CASP
Critical Appraisal Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

CASP
Critical Appraisal Skills Programme

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

CASP
Critical Appraisal Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

CASP
Critical Appraisal Skills Programme

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:	

Appendix 1.5

Full study characteristic table.

Study	Citation & Country	Dates of data collection and location	Study Sample (No. of participants/Demographic information, how long infant had been in NICU)	When in the NICU journey did study take place	Data collection method and Analysis	Core Themes & Sub-Themes
S1	Barton et al, 2021 USA	September 2018-NR 6 NICUs and two NICU transfers ward	Fathers (*n*=6) Age range (25-55+ years old) Ethnicity: White (*n*=5) Black (*n*=1) One infant (*n*=4) Twins (*n*=1) Triplets (*n*=1) All reasons for admission- Not just prematurity. Infant hospitalised for >7 days	Post discharge-3 weeks to 19 years	Semi-Structured interviews Thematic Analysis	6. Horrible Storm 7. Piece by Piece 8. I'm the father. 9. The gift of Support 10. Little fighters
S2	Cecagno et al, 2017 Brazil	November 2017-January 2018 One NICU in a teaching hospital in South Brazil.	Mothers (*n*=5) Age range (23-41 years old) Gestational age ranged from 28-35 weeks. First experience of the NICU. Admission for prematurity.	72 hours-42 days postpartum.	Semi-Structured interviews Thematic Analysis	3. The experience of mothers of premature children hospitalised in the neonatal intensive care unit. 4. Mothers' perceptions of the care received by the team in the neonatal intensive care unit.

			Infant hospitalised for >3 days			
S3	Cinar et al, 2017 Turkey	January 2009 One state hospital NICU.	Fathers (*n*=7) Age Range (22-43 years old) Turkish (*n*=7) Muslim (*n*=7) First time fathers (*n*=4) Fathers with 2 children (*n*=2) Fathers with 3 children (*n*=1) Gestational age (28-36 weeks) Admission for prematurity (< 36 weeks)	NR	Narrative interviews. Thematic Analysis	6. Suddenly being in a situation never reflected on 6.1. Not grasping the situation 6.2. Not knowing how to feel 7. First consider the baby 7.1. Putting infant first 7.2. Desire to see baby more. 7.3. Desiring to participate to care of baby or not. 8. Increasing of family responsibility 8.1. To support the mother emotionally and the need support of parents 8.2. Remaining of care of other children to father 9. Information requirements 9.1. Need to know what happen and more information necessity from professionals. 10. Needing to share experience with someone who can understand.

S4	Dadkhahtehrani et al, 2017 Iran	December 2013-January 2014 One NICU in Qom, Iran (Hazrat-e-Zahra Hospital)	Fathers (*n*=6) Age Range (23-42 years old)	Infant in NICU.	Semi-structured interviews Interpretative Phenomenological Analysis (IPA)	4. Abandonment and helplessness 1.1. Lack of financial support. 1.2. Lack of informational support 1.3. Indignation and distrust towards the hospital staff. 2. Anxiety and confusion 2.1. Family disruptions 2.2. Shock 2.3. Uncertainty. 2.4. Loss of wishes 2.5. Feelings of guilt and blame 2.6. Occupational disruption 3. Development and self-actualization 3.1. Emotional development 3.2. Spiritual development 3.3. Independence and self-efficiency 3.4. Responsibility.
S5	De Cassia et al, 2014 Brazil	March-May 2010	Mothers (*n*=9)	Infant in NICU	Phenomenological Interviews	5. Being afraid of the environment and initially touching the child.

		One NICU of a public university hospital in Rio De Janeiro.	First 5 days of their NICU experience.		Heideggerian methodology	6. Being received in the unit. 7. The chronological period 8. The monitoring of the baby's improvement.
S6	Gundogdu et al, 2022 Turkey	April-October 2019 NR	Parents (*n*=15) (Mother (*n*=11) Father (*n*=4) First time parent (*n*=8) More than one child (*n*=7) Age range (20-36) Gestational age (22-36 weeks) First NICU experience Infant hospitalised for >24 hours	Infant in NICU	Semi-structured interviews Van Manen's Hermeneutic Phenomenological Methodology.	5. Having a preterm baby 5.1. Preparedness 5.2. Inability to fulfil the parental role. 5.3. Helplessness 5.4. Guilt 5.5. Disappointment. 5.6. Strengthening of the bond between couples. 6. Intensive care experience 6.1. First visit. 6.2. Uncertainty 6.3. Fear 6.4. Not being able to participate in care. 6.5. Fatigue 6.6. Having difficulty. 7. Feelings and expectations towards nurses. 7.1. Trust 7.2. The person who knows most about your baby. 7.3. Thinking of a nurse as an ambassador 7.4. Expectations 8. Emotions about discharge and home care.

						8.1. Fear of not meeting the care requirements 8.2. Self-confidence 8.3. Hope 8.4. Need for counselling.
S7	Kim, 2020 South Korea	November 2017-January 2018. 49 tertiary hospitals in South Korea.	Mothers (*n*=232) Gestational age <37 weeks. Infant had to be in NICU >7 days.	Mothers were <18 months postpartum.	Open ended questions- 2nd Analysis Thematic Analysis	5. Family-friendly environment. 5.1. Supportive attitudes of health-care providers. 5.2. 24-hour open access visiting policy. 6. Relationship- based support. 6.1. Lack of empathetic communication skills. 6.2. Separation and detachment from the infant. 6.3. Limited opportunity for kangaroo and infant care. 7. Information and education-based support 7.1. Inconsistent guidance on infant care. 7.2. Need for development of educational content for parents. 8. System-level change 8.1. Concerns about infection control.

						8.2. Improving NICU facilities/equipment and rectifying staff shortages.
S8	Koliouli et al, 2016 France	March 2013-April 2014. One university Hospital NICU.	Fathers (*n*=48) Age range (27-52 years old) Gestational age (26-35 weeks) Infant admitted to NICU for >1 week	NR	Semi structured interviews NR	6. Relationship with infant 7. Feelings as a father 8. Relationship with medical staff 9. Relationship with partner 10. Family support.
S9	Kyno et al, 2021 Norway	Autumn 2020 NR	Parents (*n*=13) (Mother (*n*=9) Father (*n*=4) First time parents (*n*=7) More than one child (*n*=3) Infants had been hospitalised for > 14 days. COVID-19	Post discharge.	Semi-structured interviews Thematic Analysis	4. Life impacting COVID-19 regulations 4.1. The closed door. 4.2. Fight for your rights. 5. Exceptional times 5.1. Seeking joint alliance 5.2. Social media 5.3. Positive COVID-19 restrictions effect 6. Struggling to become a family. 6.1. Emotional loneliness 6.2. Paternal competency 6.3. Postponed attachment.
S10	Namusoke et al, 2021 Uganda	NR One NICU in Mulago	Mothers (*n*=51) Age range: <18 (*n*=5) 19-25 (*n*=19) 26-35 (*n*=24) 36-45(*n*=3) Gestation age (23->30 weeks)	Infant in the NICU for interviews. Post discharge for focus groups.	Semi-structured interviews and Focus groups. Thematic Analysis	7. Uncertainty about the survival of a preterm baby. 8. Feeding challenges of a preterm baby 9. Worriers about care of the baby after discharge. 10. Communication gap between mothers and

				No mothers were involved in both interviews and Focus Groups.		nurses and the perceived insensitivity of nurses. 11. Community acceptability and distain for preterm babies. 12. Financial challenges of having a preterm baby.
S11	Nazari et al, 2020 Iran	2016 2 different NICUs	Mothers (*n*=35) Age range (18-40 years old). Infant in NICU for >4 days	Infant in NICU.	Semi structured interviews Conventional Content Analysis	3. Perceived concerns. 3.1. Perception of relatively respectful behaviour of treatment team. 3.2. Attention to inadequate facilities and equipment. 3.3. Perceived physical and psycho-mental problems. 3.4. Concerns about hospitalisation. 4. Being hopeful 4.1. Awaiting discharge. 4.2. Prayers for recovery 4.3. Good feeling following signs of improvement 4.4. Positive side of hospitalisation.
S12	Osorio Galeano & Salazar Maya 2021	April-October 2020	Parents (*n*=12) (Mother (*n*=9) Father (*n*=3) Age range (20-52 years old)	Post discharge-	Semi-structured interviews	5. Needing information

	Columbia	NR	One infant (*n*=10) Twins (*n*=1) Triplets (*n*=1) Gestational age (26-34 weeks)	15 to 120 days.	Grounded Theory	5.1. Needing general information about the child. 5.2. Needing information about the pandemic 6. Limiting interaction with the children. 6.1. Limiting the physical separation. 6.2. Limiting the opportunity to learn about caring for the premature child. 7. The pandemic adding to fears. 7.1. Fear of infection. 7.2. Fear of going home amid the pandemic 8. Limited support after discharge. 8.1. Limiting the follow up. 8.2. Limiting social support after discharge.
S13	Pinar, 2020 Turkey	January-May 2016 One tertiary hospital NICU	Mothers (*n*=25) Age range (20-42 years) Gestational age (24-28 weeks) Infant in NICU for >3 days COVID-19	NR	Semi-structured interviews Content Analysis	5. The emotional and psychological difficulties of having a premature newborn. 5.1. Feeling of separation-alienation from their baby.

						5.2. Feeling isolation towards the NICU setting. 5.3. Feelings of emotional distress. 6. Lack of self-confidence. 7. Maternal- newborn interaction. 8. Maternal-health provider's interaction and expectations. 8.1. Effective communication. 8.2. Psycho-social support.
S14	Shahkolahi et al, 2018 Iran	September 2015-February 2016 2 hospitals in Iran	Fathers (*n*=13) Age range (28-37 years old) Infant in NICU for >24 hours.	Infant in NICU.	Semi-structured interviews Thematic Analysis	4. Emotions and responsibilities. 4.1. Concerns about the infant. 4.2. Concerns about the spouse 4.3. Personal concerns 4.4. Concerns about others 4.5. Concerns about diagnostic and therapeutic procedures. 5. Information needs 5.1. NICU technology and equipment 5.2. Hospital, NICU environment, physicians, and nurses.

						6. Beliefs 6.1. Faith in God and resorting to Imams. 6.2. Confidence in medical and nursing teams.
S15	Shoshi et al, 2022 Israel	March-April 2020 Large level 3 NICU.	Mothers (*n*=12) Age range (21-41 years old) Jewish (*n*=11) Muslim (*n*=1) First time mothers *(n*=7) Gestational age (25-35 weeks) Length of stay in hospital (7-176 days) COVID-19	Infant in NICU	Semi-structured interviews. Narrative Analysis	4. Expectations vs. reality and the need to constantly adapt. 5. Challenges related to COVID-19 5.1. Practical challenges 5.2. Emotional challenges. 6. Coping resources.
S16	Urbanosky et al, 2023 USA	January-June 2020 Recruitment via 3 support groups.	Fathers (*n*=28) Age range (26-49) Race (white *n*=27) (Asian *n*=1) Gestational age (24-36 weeks) Length of hospital stay (3-122 days)	Post discharge-2 weeks to 16 years	Semi-structured interviews Content Analysis	4. Vividly recalling experience. 5. Stress with work-life balance 6. Worry about their significant other.
S17	Yang et al, 2017 Singapore	November 2013-February 2014. One tertiary public hospital.	Parents (*n*=8) Mothers(*n*=6) Fathers(*n*=2) First time parents (*n*=5) Ethnicity: Chinese (*n*=2) Indian (*n*=3) White (*n*=1) Malay (*n*=1) Burmese (*n*=1)	Infant in NICU.	Semi-structured interviews Thematic Analysis	5. Negative emotions versus positive emotions. 5.1. Unexpected and shocking 5.2. Sadness and sense of loss 5.3. Questioning and blaming. 5.4. Fear and stress 5.5. Excitement, anticipation

			Gestational age (24-34 weeks) Length of stay in NICU (10- 105 days)			5.6. Concerns about taking over responsibilities. 6. Finding ways forward. 6.1. Focusing on the positive and coming to terms with the preterm birth 6.2. Turning to spiritual faith 6.3. Interacting and bonding with infant. 6.4. Preparing for baby's discharge. 7. Nature of the support received from various sources. 7.1. Information and emotional support from healthcare professionals. 7.2. Emotional support from spouse. 7.3. Instrumental and emotional support from community. 7.4. Emotional support from other parents with preterm infants. 8. Need for information and professional support. 8.1. Information regarding parenting preterm infants and resources.

						8.2. Responding to queries in time and having updated knowledge.
S18	Yu et al, 2020 China	January-May 2018 One tertiary hospital in central China	Parents (*n*=15) Fathers (*n*=5) Mothers (*n*=10) Age range (24-43 years) One baby (*n*=11) Multiple babies (*n*=4) Gestational age (27-37 weeks) Infant in NICU for > 7 days	Infant in NICU.	Semi-structured interviews Thematic Analysis	5. Mixed emotional experiences. 5.1. Sadness and guilt. 5.2. Anxiety and worry. 6. Separation from the infant. 6.1. Perceived incompetence in taking care of preterm infants. 6.2. Lack of self confidence 6.3. Lack of abilities 7. Obtained support through various sources. 7.1. Support from medical staff. 7.2. Peer support from other parents with preterm infants. 8. Desired more from healthcare professionals 8.1. Emotional needs 8.2. Information needs
Key: Not Reported (NR)						

Appendix 1.6

Quality assessment of the included studies using CASP Checklist

CASP Checklist Questions	Study																	
	S1	**S2**	**S3**	**S4**	**S5**	**S6**	**S7**	**S8**	**S9**	**S10**	**S11**	**S12**	**S13**	**S14**	**S15**	**S16**	**S17**	**S18**
1. Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Is the qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research?	Y	C	Y	Y	Y	Y	C	N	Y	C	Y	C	C	C	Y	C	Y	Y
4. Was the recruitment strategy appropriate to the aims of the research?	Y	Y	C	Y	C	Y	Y	C	Y	Y	Y	Y	C	Y	Y	Y	Y	Y
5. Were the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	C	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6. Has the relationship between researcher and participants been adequately considered?	N	N	N	C	N	C	N	N	N	N	N	N	N	N	Y	N	N	N
7. Have ethical issues been taken into consideration?	Y	Y	Y	Y	C	Y	Y	C	Y	Y	Y	Y	Y	Y	N	C	Y	Y
8.Was the data analysis sufficiently rigorous?	Y	N	C	Y	N	Y	Y	N	Y	Y	Y	C	C	N	C	C	C	Y
9. Is there a clear statement of findings?	C	C	Y	Y	C	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
10. How valuable is the research?	Y	Y	Y	Y	C	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Key: Yes (Y) Can't Tell (C) No (N)																		

Appendix 2.1

Standards for Reporting Qualitative Research (SRPR).

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 42
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 45
Introduction	
Problem formulation – Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 46-50
Purpose or research question - Purpose of the study and specific objectives or questions	Page 50
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Pages 52 &53
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Pages 54 & 55
Context - Setting/site and salient contextual factors; rationale**	Page 52
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Pages 51, 52 & 54
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Pages 50, 100 & 101

Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Pages 51-52
Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 51-52
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 55
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Pages 52-54
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Pages 52, 55 & 109
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Pages 54-55

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 56-63
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Pages 56-63

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pages 64-66
Limitations - Trustworthiness and limitations of findings	Pages 67 & 68

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Not reported

Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Not reported.

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:
O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.**
Academic Medicine, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

Appendix 2.2

MVLS College Ethics approval letter.

Appendix 2.3

NHS Management Ethical approval email.

Appendix 2.4

Participant information sheet.

https://osf.io/w6sm5

Appendix 2.5

Privacy notice.

https://osf.io/tv35e

Appendix 2.6

Reply slip.

https://osf.io/q27n8

Appendix 2.7

Pre-interview questionnaire.

https://osf.io/4jdv8

Appendix 2.8

Consent form.

https://osf.io/vstzq

Appendix 2.9

Interview schedule.

https://osf.io/596bx

Appendix 2.10

A sample of reflective journal notes.

Sample 1: 13.01.2023- Personal reflections following interview with ID586

Reflecting on my first two interviews, I am aware that I felt nervous to begin with however as the interviews progressed, I felt more confident, and I think the interviews flowed well. I was aware during my first interview that the questions were quite repetitive, and I felt that some of the information had already been provided earlier on in the interview. I was conscious of not wishing to annoy participants with repeating questions but also aware that this might just be my own bias and may not be the experience of the participants. I sought clarity from the second participant in terms of how they had found the questions when the interview ended. They were open and advised that although the questions did at times repeat topics, they noted they had found this beneficial as it meant that were able to provide more information and clarify points, they also stated that it made them think about things in more depth and provide more information. On reflection, when transcribing, I recognise that there was different information provided at each answer and that this has been beneficial in enriching the data.

I am also aware of bringing in my clinical skills to the interview- I used summaries and reflected information in the hope of allowing my participant to feel heard and understood but I am also aware that this has the potential to introduce my own bias and influence the participant. I do think that this allows the participant the opportunity to correct me, and I wonder if this participant felt comfortable to do this due to their skills and training as a Clinical Psychologist and their awareness of my role.

Have discussed this with supervisor and was advised that active listening skills and reflection is okay if there is not too much leading or providing too much information.

Sample 2: 21.02.23 Discussion with academic supervisor following 6th interview.

Discussion around my own bias and what I was bringing to the interviews based on my professional role and the specialist placement I am currently in. Discussed how I feel that I might be viewed by participants and the impact this has on my questioning and knowledge of the area. This is a consideration for reflectivity and how I may influence the result.

Sample 3: 16.05.23 Supervision following initial coding/development of themes with field and academic supervisor.

We explored how my placement within an MNPI service has led me to view the data differently and gain experience about what it is like for families within this context rather than just researching this area without the clinical experience. Explored how clinical experience can enrich and influence research. Discussed how I will be able to pull on the nuances I am aware of after spending six months within this environment in my coding and framework and the impact that this placement and experience has had during the research process.

Appendix 2.11

Final framework used for indexing

1. **Current practice for assessment and measuring parental stress in NICU.**
    - 1.1. Clinical interview for assessment is key.
    - 1.2. Assessment specific to pregnancy/neonatal journey
    - 1.3. No standard way for measuring parental stress.
    - 1.4. Items from parental stress scales incorporated in assessment without the use of the tool.
    - 1.5. Using bespoke/non- standardized measures for exploring parental stress
    - 1.6. Using other standardized outcome measures in assessment process.
2. **Experience of using outcome measures for parental stress in the NICU**
    - 2.1. Not using existing parental stress measures.
    - 2.2. No knowledge of existing measures.
    - 2.3. No access to tools
    - 2.4. Considered use previously.
    - 2.5. Ambiguity about using existing measures.
3. **Strengths/Positives of existing outcome measures.**
    - 3.1. Aids assessment process
    - 3.2. Factors on PSS-NICU are relevant.
    - 3.3. Proving our worth
    - 3.4. Normalizing distress
    - 3.5. Useful as a screen
    - 3.6. Can measure change over time.
    - 3.7. Gaining feedback
4. **Barriers/Limitations of existing outcome measures**
    - 4.1. One size doesn't fit all/Can't capture the entire experience.
    - 4.2. This is a normal response- Why label it? 'Pathologizing distress'.
    - 4.3. What is the construct being measured?
    - 4.4. Lack of sensitivity- 'Everyone's at the ceiling.'
    - 4.5. The physical 'tool'- Questions on paper.
    - 4.6. Use as a screening tool
    - 4.7. Timing
    - 4.8. Language
    - 4.9. Length of tool
    - 4.10. Who completes it
    - 4.11. Tracking change?
    - 4.12. Parent's ability to reflect in acute distress
    - 4.13. Mis-attuned to families' needs.
    - 4.14. Research tool
5. **Influences use of outcome measures (Any kind)**
    - 5.1. Service requirements
    - 5.2. Previous roles/Professional background.
    - 5.3. Clear rationale for use.
    - 5.4. Negative views/biases of outcome measures
    - 5.5. Positive views/biases of outcome measures.

5.6. Clinician's discomfort with measures.
5.7. Doesn't fit the NICU experience.

6. A new measure for parental stress.

6.1. Do we need one? Does it add anything?
6.2. Tool already exists.
6.3. It is needed.
6.4. Trauma focused items
6.5. Screening for potential mental health difficulties-? Predictive function
6.6. Transition home/discharge from hospital.
6.7. Feeding
6.8. Bonding
6.9. Broad and holistic.
6.10. Easy to use.
6.11. Appropriate language
6.12. Design of tool- Visual, fits on one page
6.13. Here and now focused.
6.14. Facilitated support/intervention offered.
6.15. Length

7. Important factor in Ax process/NICU

7.1. Importance of therapeutic relationship.
7.2. Assessment as an evolving process.
7.3. Assessment tailored to their needs/journey.
7.4. Being able to intervene

8. Psychology in the NICU environment.

8.1. NICU as a unique experience/journey. 'Roller-coaster'
8.2. The role of psychology is different here.
8.3. Protective of the parents.
8.4. Parents aren't accessing support for mental health.
8.5. What's our intervention?
8.6. Psychology in infancy- Development of services.
8.7. Confident
8.8. Less confident

Appendix 2.12

Major Research Project (MRP) proposal.

https://osf.io/sv4kh