

# What matters to families about the healthcare of preterm or low birth weight infants: A qualitative evidence synthesis

Lisa Hurt<sup>a,\*</sup>, David Odd<sup>a,2</sup>, Mala Mann<sup>b,3</sup>, Hannah Beetham<sup>c,4</sup>, Emma Dorgeat<sup>c,5</sup>, Thomas CW Isaac<sup>d,6</sup>, Annie Ashman<sup>e,7</sup>, Fiona Wood<sup>a,8</sup>

<sup>a</sup> Division of Population Medicine, Cardiff University School of Medicine, Cardiff, UK

<sup>b</sup> Specialist Unit for Review Evidence, Cardiff University, Cardiff, UK

<sup>c</sup> Cardiff University School of Medicine, Cardiff, UK

<sup>d</sup> Yeovil District Hospital, Yeovil, UK

<sup>e</sup> Public Health Wales, Cardiff, UK

## ARTICLE INFO

### Keywords:

Preterm  
Low birth weight  
Family  
Qualitative  
Views  
Healthcare  
Synthesis

## ABSTRACT

**Objective:** We examined what matters to families about the healthcare provided to preterm or LBW infants in hospital and the community, to ensure that care meets the needs of infants and parents.

**Methods:** We searched databases to identify eligible studies examining the views and expectations of families. Study quality was assessed using the CASP checklist for qualitative studies. The GRADE-CERQual approach was used to assess confidence in review findings. Studies were sampled and data analysed using thematic synthesis.

**Results:** 222 studies (227 papers) were eligible for inclusion. 54 studies (57 papers) were sampled based on data richness, methodological quality, and representation across settings. Eight analytical themes were identified. Confidence in results was moderate to high. What mattered was a positive outcome for the child; active involvement in care; being supported to cope at home after discharge; emotional support; the healthcare environment; information needs met; logistical support available; and positive relationships with staff.

**Conclusion:** Although parents and family members reported a variety of experiences in the care of their infant, we found high consistency in what matters to families.

### Practice Implications:

This review identifies approaches to improve experiences of parents which are consistent with the Family Centred Care model of healthcare.

## 1. Introduction

Around 1 in 10 infants worldwide is born preterm or with a low birth weight (less than 2500 g (LBW)), with a high risk of mortality and morbidity [1–3]. Survival has improved given recent advances in neonatal care [4,5]. However, these infants often require complex and prolonged medical intervention, with survivors at increased risk of

lifelong disability and poor quality of life [6,7]. While risks can be reduced through interventions provided before or during pregnancy and after birth [8], these births represent a major cause of poor health globally [9,10].

There have been continuous and substantial changes in the delivery of neonatal care over the last decades. New evidence has also emerged for specific interventions including kangaroo mother care, probiotics,

\* Corresponding author.

E-mail address: [hurtl@cardiff.ac.uk](mailto:hurtl@cardiff.ac.uk) (L. Hurt).

<sup>1</sup> ORCID 0000-0002-2741-5383

<sup>2</sup> ORCID 0000-0002-6416-4966

<sup>3</sup> ORCID 0000-0002-2554-9265

<sup>4</sup> ORCID 0000-0001-6166-807X

<sup>5</sup> ORCID 0000-0002-9404-0040

<sup>6</sup> ORCID 0000-0001-7181-2231

<sup>7</sup> ORCID 0000-0002-3181-4168

<sup>8</sup> ORCID 0000-0001-7397-4074

and different methods of feeding or giving respiratory support [11]. As a result, there has been renewed focus on ensuring high-quality and equitable care for small and sick neonates worldwide [12]. Family-centred care, where family members work with healthcare professionals to play an active role in providing emotional, social, and developmental support to the vulnerable infant, is known to be beneficial [13], but is not available everywhere. The impact of a preterm or LBW birth on families is also increasingly understood, with consequences for attachment, bonding, and parental health and wellbeing after birth and beyond [14,15].

An updated World Health Organization (WHO) guideline on healthcare for preterm or LBW infants has recently been developed [11]. To ensure that care meets the needs of infants and parents, and to identify where further intervention development is required, an understanding of families' requirements and values was needed to inform the scope of the guideline [16,17]. The aim of this qualitative evidence synthesis (QES) was to systematically review literature that studied the views or perspectives of families about the care provided by health services for preterm or LBW infants after birth in hospital and in the community.

## 2. Materials and Methods

The protocol for this QES was registered with PROSPERO on 6 July 2021 (registration number CRD42021261934). The review is reported in accordance with the PRISMA guidelines and the Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) statement [18].

### 2.1. Eligibility criteria: Topic of interest

We used the PEO (Population, Exposure, Outcomes) framework to specify the inclusion criteria (Table 1).

We aimed to synthesise the views of family members who had experience of the healthcare that the infant or family had received. This could include mothers, fathers, parents, carers or guardians, grandparents, siblings, or other family members. As this is an inclusive list, we will refer to family members as "carers" throughout the review. The views of healthcare workers (paid or unpaid) were outside the remit of the review. Data from all countries and all healthcare settings (home, community, primary, secondary, and tertiary care) were eligible for inclusion. A preterm infant was defined as an infant born alive before 37 weeks of pregnancy [19]. Low birth weight was defined as weight at birth of less than 2500 g [20].

We excluded studies that only provided information that described families' experiences (for example, how long the infant was in hospital, or where the parents stayed). We did not exclude studies that explored parents' views about specific interventions (such as kangaroo mother

**Table 1**  
Review Population, Exposure, Outcomes.

|                                      |  |
|--------------------------------------|--|
| <b>Population and their problems</b> | Included populations were: <ul style="list-style-type: none"> <li>- Mothers, fathers, parents, carers or other family members with first-hand experience of healthcare for a preterm or low birth weight infant;</li> <li>- In all study settings (high and low resource);</li> <li>- In all healthcare settings (home, community, primary, secondary and tertiary care).</li> </ul> |
| <b>Exposure</b>                      | Healthcare delivered from birth to 24 months of age for: <ul style="list-style-type: none"> <li>- Infants born preterm (&lt;37 weeks or sub-categories);</li> <li>- Infants born with low birth weight (&lt;2500 g or sub-categories).</li> </ul>  |
| <b>Outcomes or themes</b>            | Qualitative or mixed methods studies examining views or values, including: <ul style="list-style-type: none"> <li>- What matters to, or is important to, or is valued by families;</li> <li>- What they find acceptable and not acceptable in the healthcare of their infant.</li> </ul>   |

care). However, the information we extracted from those studies related to how the intervention contributed to parents' views of healthcare in general, rather than their views about the intervention.

In our protocol, we specified that data collected from birth until the infant was 24 months of age would be included. However, as we screened studies, we found several high-quality studies that had collected information when children were older. We therefore decided to include these studies, on condition that the data referred to care received before the infant was 24 months of age.

### 2.2. Eligibility criteria: Types of studies

Primary studies that used qualitative study designs such as ethnography, phenomenology, case studies, and qualitative process evaluations were eligible for inclusion. We included studies that used qualitative methods for data collection (for example, focus groups, individual interviews, observation, diaries, document analysis, open-ended survey questions) and for data analysis (for example, thematic analysis, framework analysis, grounded theory). We excluded studies that collected data using qualitative methods but did not analyse these data using qualitative analysis methods (for example, open-ended survey questions where the response data are analysed using descriptive statistics only). Mixed methods studies for which it was possible to extract the data that were collected and analysed using qualitative methods were eligible.

To ensure that the data reflected the views of a contemporary cohort of parents, while still ensuring that we captured all key papers, studies published in or after 2000 were eligible. We excluded studies that had only been published as conference abstracts or PhD or Masters theses. Studies had to be published in English (the language of the review team) to ensure that themes were appropriately identified, understood and represented.

### 2.3. Reflexive note

We are a multi-disciplinary team including a neonatologist, child health epidemiologist, qualitative methodologist, information specialist, medical students, and specialty registrars in public health and paediatrics. None of the team had personal experience of being a parent of a preterm or LBW infant. Due to funding and time restrictions, we were not able to include Patient and Public Involvement (PPI) input into our review. In addition, given the global remit of the work, we felt that any PPI input would have needed to be more extensive than was feasible to provide valid benefits. We maintained a reflexive stance throughout the review process. Our varied backgrounds and different levels of topic expertise helped us to remain mindful of our presuppositions. We encouraged each other to consciously acknowledge our own professional assumptions and biases, and supported each other to minimise the risk of these skewing our interpretation of our findings. The senior author kept a reflexive journal to document and reflect on progress and decisions made.

### 2.4. Information sources

We searched African Journals Online, ASSIA, CINAHL, Cochrane Central Register of Controlled Trials, LILACS, MEDLINE, PsycINFO, Sociological Abstracts, Web of Science, and reference lists of eligible studies for primary studies published between 1 January 2000 and 1 December 2022. We also reviewed the reference lists of all included studies and key references such as relevant systematic reviews.

### 2.5. Search strategy

Searches were pre-planned, with key words and Medical Subject Headings (MeSH) terms for the three main topic areas (qualitative research and values; preterm and low birth weight; and healthcare)

identified and combined using “OR”. The three groups were combined using “AND”, and limited to papers published in or after 2000. A full list of search terms and the results of an initial scoping search conducted in MEDLINE are presented in [Supplementary Material Appendix A](#). The MEDLINE search strategy was adapted for the other databases, with searches in some (such as African Journals Online and LILACS) limited to key words as these do not include MeSH terms. No language restrictions were placed on the searches. Instead, we identified English language papers during the screening process. The search was first run on 14 June 2021, and repeated on 1 December 2022 to capture new papers.

## 2.6. Study screening

Searches from individual databases were downloaded into Endnote 20 and duplicates removed. Studies were selected according to the established eligibility criteria using a two-step screening process. Titles and abstracts were screened for inclusion independently by two of six reviewers (LH, DO, HB, ED, AA or TI). Full-text versions were obtained for the papers potentially meeting the inclusion criteria and were screened independently by two of five reviewers (LH, DO, HB, ED, or FW). Disagreements were resolved by discussion.

## 2.7. Data extraction

The data extraction form collected details on the characteristics of included studies and participants (including population studied, birth outcomes, healthcare setting, inclusion and exclusion criteria, recruitment method, and data collection and analysis methods); results (including themes identified); and quality assessment items (see [Supplementary Material Appendix B](#)). The form was piloted using two studies. Data from each paper were extracted independently by two reviewers (HB, ED, or LH). Multiple publications from the same study were linked and compared for completeness and contradictions.

## 2.8. Quality assessment

We used the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies to assess the quality of all eligible studies [21]. Two reviewers (HB, ED) completed the CASP assessment independently for each eligible paper. A third reviewer (LH, DO or FW) evaluated all discrepancies. These were resolved by discussion. Each included paper was categorized as being of good, average, or low quality, based on a qualitative assessment of all elements of the CASP checklist.

## 2.9. Study sampling

Qualitative evidence synthesis aims to identify variation in concepts rather than an exhaustive sample of papers. When large numbers of eligible studies are identified, the Cochrane Effective Practice and Organisation of Care (EPOC) Qualitative Evidence Syntheses guidance recommends sampling studies because too much data can impair analysis quality [22]. We therefore pre-specified that we would include approximately 50 papers in our analysis. The sampling criteria were studies that scored three or higher on a data richness scale [22] (see criteria in [Supplementary Material Appendix C](#)); were good or average quality; and were from a range of different countries with varying resources. All studies that both scored four or five on data richness *and* were classified as “good” were included. All studies with both data richness scores of three or below *and* quality scores of “average” or “poor” were excluded. Five team members (LH, DO, HB, ED, FW) prioritised the remaining studies by consensus, based on the study setting (to ensure that data from the broadest range of countries were included) and data richness (for countries with multiple data-rich studies).

## 2.10. Synthesis methods

Thematic synthesis techniques were used for analysis and synthesis [23]. This method draws on concepts used for thematic analysis in qualitative research in primary studies as a method of identifying and developing themes within the data. Included papers were imported into NVivo12 [24], so that information from all sections could be used in data coding. Data were inductively coded using a line-by-line method according to its meaning and content (descriptive coding). Codes could be structured (in tree form) or in free form without hierarchical structure. New codes were created as necessary as we progressed through the papers and similar, or related, codes were grouped. Finally, coded data were synthesised into analytical themes which captured, and brought together, groupings of the descriptive themes. The initial analysis was conducted by FW, and was then revised in discussion with the author group.

## 2.11. Certainty assessment

We used GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research) to assess our confidence in each finding [25]. This assessment is based on four components: 1) methodological limitations of included studies; 2) coherence of the review finding; 3) adequacy of the data contributing to a review finding; and 4) relevance of the included studies to the review finding [26–29]. The author group made a judgement (based on a consensus view) about the overall confidence (high, moderate, low, or very low) in the evidence supporting each finding. All findings started as high confidence and were downgraded if there were concerns regarding any of the GRADE-CERQual components.

## 3. Results

### 3.1. Included studies

8294 studies were identified by database screening once duplicates were removed (see [Fig. 1](#)). 7476 studies were excluded by title and abstract screening. 816 full text papers were assessed for eligibility. Of these, 222 studies (reported in 227 papers) were eligible for inclusion. The most common reason for excluding studies at the full-text stage was that they did not present qualitative data ( $n = 173$ ). We selected 54 studies (reported in 57 papers) from 28 countries for inclusion in the analysis using our pre-specified criteria [30–86]. References of the studies that were eligible but not included are given in [Supplementary Material Appendix D](#).

### 3.2. Study and participant characteristics

[Table 2](#) shows the characteristics of the included studies. 53 of the 57 papers were published in 2012 or later. Most (36 of 54 studies) were conducted in high income settings, with eleven from countries classified as upper-middle income, four lower-middle income settings, two in low-income countries (Malawi and Uganda), and one in Taiwan (which is not on the World Bank list). Qualitative interviews were used for data collection in 43 of 54 studies. Three studies used focus groups, four used a combination of interviews, participant observation or focus groups, one analysed free-text responses from a questionnaire, two used data collected via a voice-recording App, and one asked the participants to keep a daily journal. 36 studies examined in-hospital care in a neonatal unit, although the level of care provided at these units varied according to the setting. Four studies examined views of community care, and fourteen studies collected data on more than one setting or aspect of care (including preparation for discharge, transition from hospital to community care, or transfers between hospitals). The selected studies had high scores on data richness (37 studies scored four, and six studies scored five) and were of high quality (48 studies were assessed as “good”

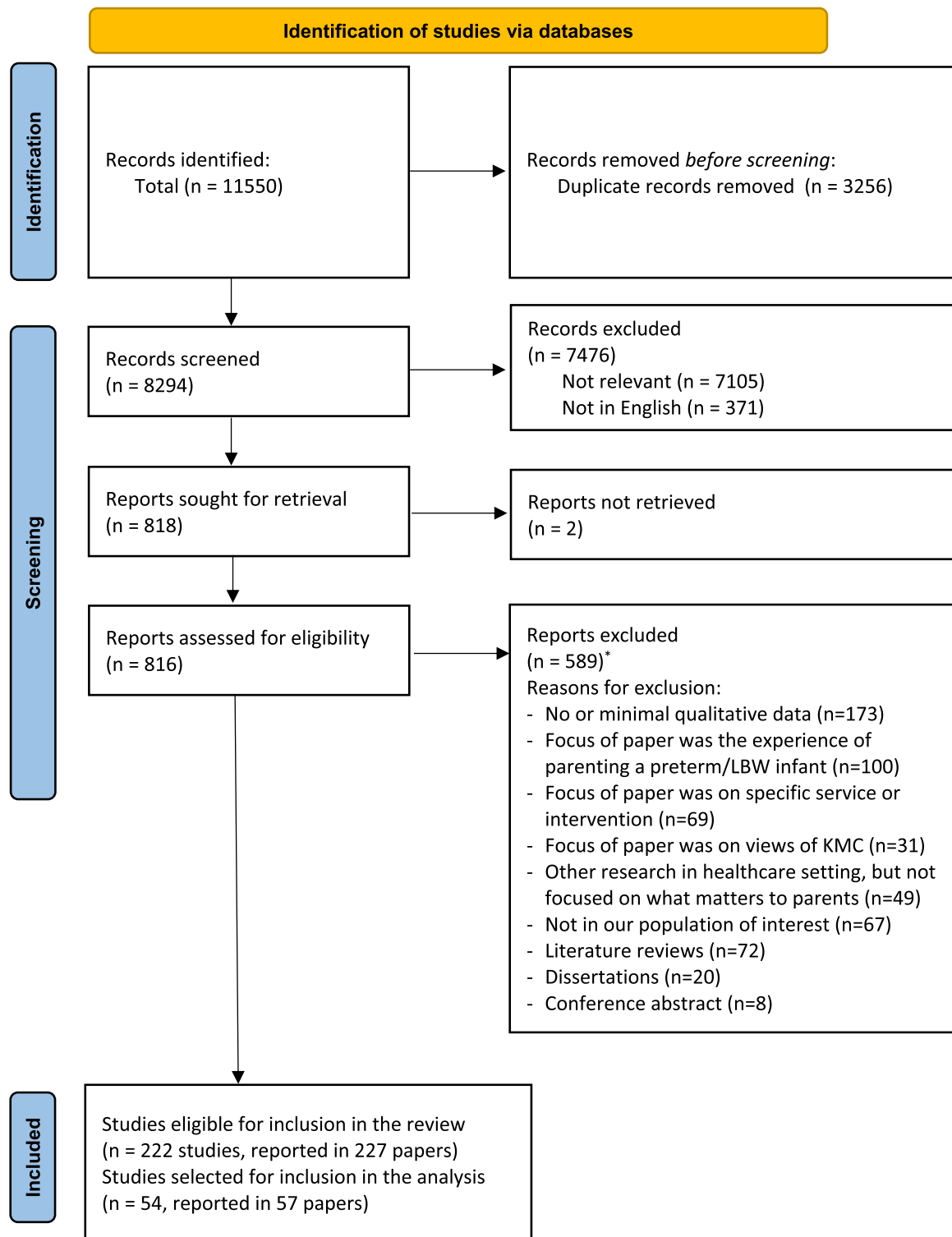


Fig. 1. PRISMA flow diagram.

after examining CASP criteria).

Table 3 shows the characteristics of the study participants. Our analysis is based on the views of 1280 caregivers included in the primary studies. 19 studies included mothers only, seven recruited fathers only, 26 included parents (mothers and/or fathers) and two recruited caregivers (including mothers, fathers and grandparents). The patient population was preterm infants in 35 studies, preterm and/or low birth weight in 18 studies, and low birth weight infants in one study. Nine studies included very preterm (<32 weeks) infants, and four included

extremely preterm (<28 weeks) infants. Specified birthweight limits, observed birthweight ranges, the ages of the infants/children at the time of the study, and characteristics of the carers were not consistently reported. Five studies collected some of their data when the children were older than 24 months, with the oldest children being 16 years old.

### 3.3. Analysis findings

We identified eight analytic themes. Within these, there were 31

**Table 2**  
Characteristics of the sampled studies (n = 54).

| Author / Date   | Aim of study (as reported in the papers)  | Country (income)*               | Data collection dates | Methods  | Healthcare setting of interest            | Recruitment method  | Data richness score | CASP rating |
|-----------------|---|---------------------------------|-----------------------|--|---|---|---------------------|-------------|
| Abeasi 2020     | To explore challenges of mothers with preterm infants during hospitalisation in a tertiary institution in Nigeria   | Nigeria (lower-middle)          | 2019                  | Qualitative interviews (location not reported)<br>Content analysis   | Neonatal unit                             | Purposive sampling from SCBU at a teaching hospital   | 4                   | Good        |
| Adama 2017      | To explore Ghanaian fathers' experiences of caring for preterm infants in the neonatal unit after discharge   | Ghana (lower-middle)            | Feb-June 2015         | Qualitative interviews (conducted in family home)<br>Thematic analysis, using a narrative space framework  | Neonatal unit & community                 | Recruited from four government hospitals as part of a larger study; no further details reported   | 4                   | Average     |
| Adcock 2021     | To give voice to the experiences, views and attributions of whānau (family collective) of preterm Māori infants.  | New Zealand (high income)       | July 2017-Jan 2019    | Qualitative interviews in form of focused life story<br>Interpretative phenomenological analysis   | Neonatal unit and community               | Recruited from four large urban tertiary level NICUs.   | 5                   | Good        |
| Amorim 2019     | To explore needs of parents of very preterm infants hospitalised in neonatal intensive care units according to their socioeconomic position, obstetric history and infant's characteristics               | Portugal (high)                 | Nov 2013-April 2014   | Mixed methods (qualitative element = interviews; conducted in the family home (n = 19), at a university (n = 6) or in hospital (n = 1))<br>Thematic content analysis | Neonatal unit                             | Recruited from all seven public level III NICU in the Northern Health Region<br>Purposive sampling from those who had completed quantitative questionnaires                   | 4                   | Good        |
| Arnold 2013     | To assess parents' first experiences of their very preterm infants and the neonatal intensive care unit   | UK (high)                       | Not reported          | Qualitative interviews (conducted in hospital or at the family home)<br>Thematic analysis  | Neonatal unit                             | Recruited from three NICU in tertiary care hospitals in South East England<br>All eligible parents invited by letter and sent reminder letter by research nurse               | 3                   | Good        |
| Aydon 2018      | To explore the experiences of parents with infants born between 28 and 32 weeks' gestation during transition through the neonatal intensive care unit and discharge                                       | Australia (high)                | Oct 2014-Feb 2015     | Qualitative interviews (pre- and post-discharge; location not reported) and an online survey<br>Thematic analysis  | Neonatal unit & transition post-discharge | Recruited at a tertiary maternity hospital<br>Parents invited by neonatal nurse researchers not directly involved in infant care  | 4                   | Good        |
| Blomqvist 2012  | To describe fathers' experiences of providing kangaroo mother care to their preterm infants   | Sweden (high)                   | 2009                  | Qualitative interviews (conducted at family home)<br>Thematic content analysis   | Neonatal unit                             | Recruited from NICUs in two hospitals<br>Questionnaire given to all fathers on NICU with option to be invited for interview; all who agreed approached by mail and phone call | 4                   | Good        |
| Brødsgaard 2015 | An evaluation of an Early Discharge Programme model for preterm infants based on family-centred care, to describe its impact on the infants and families.   | Denmark (high)                  | Not reported          | Mixed methods (qualitative element = focus groups, conducted in hospital after discharge)<br>Deductive theory-driven and directed content analysis                   | Neonatal unit & community                 | Purposive sampling of parents who had been enrolled in an Early Discharge Programme for preterm infants; parents contacted by telephone after discharge                       | 4                   | Good        |
| Chang Lee 2009  | To explore Taiwanese mothers' parenting experiences when their preterm infants were in NICUs  | Taiwan (not in World Bank list) | Not reported          | Qualitative interviews and participant observation (both in NICU)<br>Grounded theory analysis  | Neonatal unit                             | Mothers recruited from major neonatal care centre; no further details reported  | 4                   | Average     |
| Dorner 2020     | To determine where, and how, neonatal intensive care unit parents want to receive early neurodevelopmental screening information about their child's future risk of cerebral palsy and other disabilities | USA (high)                      | March 2018-June 2018  | Qualitative interviews (location not reported)<br>Thematic content analysis  | Neonatal unit                             | Study conducted at a level IV NICU and an associated level III NICU; parents approached at bedside by researcher to explain the study and obtain consent                      | 4                   | Good        |
| dos Santos 2014 | To understand the meaning of home visits by neonatal  | Brazil (upper-middle)           | Not reported          | Qualitative interviews (conducted at follow-up)  | Community (with a focus                   | Participants were part of another project; mothers were   | 4                   | Good        |

(continued on next page)

Table 2 (continued)

| Author / Date          | Aim of study (as reported in the papers)   | Country (income)*     | Data collection dates | Methods  | Healthcare setting of interest              | Recruitment method  | Data richness score | CASP rating |
|------------------------|--|-----------------------|-----------------------|--|---|---|---------------------|-------------|
|                        | nurses for mothers of premature infants  |                       |                       | clinic)<br>Thematic content analysis   | on home visits)                             | approached by female graduate students when they attended a follow-up clinic  |                     |             |
| Feeley 2013            | To explore what fathers perceive to be facilitators or barriers to their involvement with their infants  | Canada (high)         | Not reported          | Qualitative interviews (conducted in hospital whilst infant was admitted)<br>Thematic content analysis   | Neonatal unit                               | Participants from two NICUs in a major Canadian urban centre<br>Approached by clinical staff members to obtain permission for researcher to contact them                                    | 3                   | Good        |
| Fernandez Medina 2021  | To explore and describe the experiences of parents of technology-dependent extremely preterm infants of socio-family support after hospital discharge  | Spain (high)          | Oct 2019- Dec 2019    | Qualitative interviews (conducted by phone after discharge)<br>Analysis using philosophical hermeneutics | Community & outpatient care                 | Purposeful sampling from four Spanish organisations that support families with preterm infants; organisations received a letter and identified participants, who then contacted main author | 3                   | Good        |
| Finlayson 2014         | To explore mothers' perceptions of family centred care in neonatal intensive care units in England   | UK (high)             | Not reported          | Qualitative interviews (conducted in hospital whilst infant was admitted)<br>Thematic networks analysis  | Neonatal unit                               | Convenience sample identified by the admissions officer at three NICUs in north west England  | 5                   | Good        |
| Franck 2017            | To discover parents' views, experiences, concerns, and recommendations about the care provided to them and their babies throughout the perinatal and neonatal healthcare journey   | UK (high)             | Not reported          | Focus groups (conducted in "local setting")<br>Thematic content analysis                                 | Neonatal unit & post-discharge care         | Parents of infants who received care in 1 of the 7 NICUs in Northern Ireland were invited to participate via a notice posted on the TinyLife Facebook page.                                 | 4                   | Good        |
| Gallegos-Martinez 2013 | To identify and analyse the significance of participation for patients in a Neonatal Unit of a maternity hospital in San Luis Potosí   | Mexico (upper-middle) | Not reported          | Qualitative interviews (location not reported)<br>Thematic content analysis                              | Neonatal unit                               | Recruited from level II neonatal unit in a public maternity hospital; no further details provided   | 4                   | Average     |
| Glazer 2021            | To understand how a racially and ethnically diverse sample of mothers experienced high-risk obstetric and neonatal care, and whether or not there were differences in these experiences by race and ethnicity that may suggest reasons for variation in quality of care and outcomes | USA (high)            | Not reported          | Focus groups (location not reported)<br>Thematic analysis  | Neonatal unit                               | Purposive, convenience sample from deliveries in a New York medical centre; accessed through medical records then contacted by telephone and via flyers in hospital-affiliated clinics      | 4                   | Good        |
| Granrud 2014           | To describe how the parents of premature infants experience the transportation of their infant from the NICU at a university hospital to a unit at a local hospital  | Norway (high)         | April -June 2011      | Qualitative interviews (conducted in hospital or at family home)<br>Inductive content analysis           | Neonatal unit & transfers between hospitals | Consecutive selection from two NICUs at two hospitals and retrospective recruitment of additional participants  | 4                   | Good        |
| Guillaume 2013         | To explore, through parents' accounts, how an early bond with their very premature child is established and to identify their experiences of caregivers, and the concrete things that helped and hindered them   | France (high)         | Nov 2009- March 2012  | Qualitative interviews (conducted in hospital whilst infant was admitted)<br>Discourse analysis          | Neonatal unit                               | Recruited from three tertiary care centres in Paris; identified and approached by nurses participating in the research  | 4                   | Good        |
| Gundogdu 2022          | To examine in detail the experiences of parents with premature babies about having a premature baby and their experiences with the hospitalization process of their babies in the neonatal intensive care unit   | Turkey (upper-middle) | April 2019- June 2019 | Qualitative interviews<br>Data analysed using Van Manen's phenomenological methodology                   | Neonatal unit                               | Purposeful sampling at one NICU. Parents were approached by a researcher and consented by a second researcher.  | 5                   | Average     |

(continued on next page)



Table 2 (continued)

| Author / Date      | Aim of study (as reported in the papers)   | Country (income)*           | Data collection dates | Methods   | Healthcare setting of interest                     | Recruitment method   | Data richness score | CASP rating |
|--------------------|--|-----------------------------|-----------------------|---|--|--|---------------------|-------------|
| Hägi-Petersen 2021 | To gain in-depth knowledge of mothers' and fathers' experiences of the whole trajectory of an early in-home care programme supported by video consultations with a neonatal nurse  | Denmark (high)              | Sept 2018-Jan 2020    | Qualitative interviews (conducted at the family home)<br>Inductive content analysis   | Neonatal unit & community (focus was in-home care) | Convenience sample of parents recruited from two neonatal wards that offered early in-home care programmes; approached by neonatal nurse on ward   | 4                   | Good        |
| Hendriks 2017      | To explore parental attitudes and values in the end-of-life decision-making process of extremely preterm infants (gestational age < 28 weeks)  | Switzerland (high)          | Not reported          | Qualitative interviews (conducted in location selected by parents)<br>Thematic content analysis using elements of grounded theory         | Neonatal unit                                      | Purposive sample recruited using letters from attending neonatologist and former director of neonatology.  | 4                   | Good        |
| Hua 2021           | To describe the facilitating/inhibiting factors of preparation for preterm infant discharge and recommendations for increasing discharge readiness from parents' and healthcare providers' perspectives based on Meleis's Transitions Theory | China (upper-middle)        | May-July 2018         | Qualitative interviews conducted in NICU<br>Data were inductive and deductively analysed using content analysis.                          | Neonatal unit and post-discharge care              | Purposive sampling to recruit parents from NICU in tertiary hospital. Researchers were introduced to parents by a nurse in the setting.  | 4                   | Average     |
| Ignell Modé 2014   | To explore fathers' perception of information received during their infants' care at a NICU  | Sweden (high)               | Not reported          | Qualitative interviews (conducted in hospital whilst infant was admitted)<br>Thematic content analysis                                    | Neonatal unit                                      | Strategic sampling to obtain varied father-infant pairs from two NICUs; no further details reported  | 4                   | Good        |
| Jantsch 2021       | To analyse the Health Care Network (dis)articulation of late and moderate premature infants in the first year of life  | Brazil (upper-middle)       | Not reported          | Qualitative interviews (conducted at family home)<br>Thematic content analysis  | Community  | Convenience sample recruited from the Obstetric Center with potential participants identified from the birth registration book   | 4                   | Good        |
| Kim 2020           | To assess mothers' perspectives on their NICU experiences and their unmet needs within the South Korean cultural context   | South Korea (high)          | Nov 2017-Jan 2018     | Free text comments in a questionnaire (delivered online)<br>Thematic content analysis, guided by critical incident technique (CIT) method | Neonatal unit                                      | Survey conducted using participants recruited via online postings on three community portals exclusively by parents of preterm infants. Mothers with preterm infants in four hospitals also recruited in person by author at NICU discharge. All mothers provided with \$4 gift certificate incentive. | 4                   | Good        |
| Klawetter 2019     | To contribute an in-depth understanding of maternal engagement and the NICU experience from the perspective of mothers of preterm infants in the NICU  | USA (high)                  | June-Dec 2017         | Qualitative interviews (conducted in hospital whilst infant was admitted)<br>Thematic analysis  | Neonatal unit                                      | Purposive sampling from two NICUs; \$20 gift card incentive given to participants  | 4                   | Good        |
| Leonard 2008       | To explore parents' lived experience of providing kangaroo care to their preterm infants in a tertiary hospital in Cape Town   | South Africa (upper-middle) | Not reported          | Qualitative interviews (conducted in hospital whilst infant was admitted)<br>Thematic analysis  | Neonatal unit                                      | Purposefully sampled parents from neonatal nursery and kangaroo care ward at a tertiary maternity hospital   | 4                   | Good        |
| Lian 2020          | To explore coping strategies of fathers of very low birth weight infants in NICU   | Singapore (high)            | Feb -Nov 2016         | Qualitative interviews (conducted in hospital whilst infant was admitted)<br>Thematic content analysis                                    | Neonatal unit                                      | Convenience sampling in level III NICU; fathers approached after 72 + hours stay by member of clinical staff, then contacted by research team  | 3                   | Good        |
| Liu 2019           | To explore support for mothers and fathers in single-family rooms of a NICU  | Canada (high)               | July 2017-May 2018    | Qualitative data collected through diary voice app (for 48 h period)<br>Thematic content analysis   | Neonatal unit                                      | Convenience sampling from a level III NICU; identified by NICU nurses who assisted with recruitment  | 4                   | Good        |

(continued on next page)

Table 2 (continued)

| Author / Date                         | Aim of study (as reported in the papers)  | Country (income)*       | Data collection dates | Methods   | Healthcare setting of interest | Recruitment method  | Data richness score | CASP rating |
|---------------------------------------|---|-------------------------|-----------------------|---|--------------------------------|---|---------------------|-------------|
| Lomotey 2020                          | To describe the lived experiences of mothers with preterm infants at a Mother and Baby Unit of a tertiary hospital  | Ghana (lower-middle)    | Not reported          | Qualitative interviews (conducted in hospital whilst infant was admitted)<br>Thematic analysis                        | Neonatal unit                  | Purposive sampling on the preterm unit; mothers recruited by researchers  | 4                   | Good        |
| Lorié 2021                            | To explore parents' needs and perceived gaps concerning communication with healthcare professionals during their preterm infants' admission to NICU   | The Netherlands (high)  | April – May 2020      | Qualitative interviews (conducted using online video conferencing tool)<br>Thematic analysis                          | Neonatal unit                  | Assisted by 'Kleine Kanjers' support network through online announcement; parents consecutively recruited based on order of registration                                      | 4                   | Good        |
| Lundqvist 2019                        | To present parents' lived experience of having a preterm infant cared for at the neonatal unit until discharge from hospital-based neonatal home care   | Sweden (high)           | Not reported          | Qualitative interviews (conducted at the family home)<br>Phenomenological analysis                                    | Neonatal unit & community      | Recruited by three nurses in a level IIb NICU; 19 couples interviewed as part of a broader study, and the 6 couples providing the richest narrative included in this analysis | 3                   | Good        |
| Merritt 2022                          | To explore the needs of fathers who previously had a premature infant in the NICU   | USA (high)              | Jan – June 2020       | Qualitative interviews conducted via zoom<br>Content analysis   | Neonatal unit                  | Parent support organisations distributed information via social media and fathers were encouraged to contact research team.   | 5                   | Good        |
| Mihae 2021                            | To clarify and define the concept of nursing support as perceived by mothers of preterm infants   | South Korea (high)      | Nov 2017-March 2018   | Qualitative interviews (location not reported)<br>Thematic analysis   | Neonatal unit                  | First participant enrolled by nurse at NICU, then snowball sampling   | 4                   | Good        |
| Namusoke 2021                         | To explore the lived experiences of mothers with preterm babies admitted to NICU in a low resource setting  | Uganda (low)            | Not reported          | Qualitative interviews and focus groups<br>Manual thematic analysis   | Neonatal unit & community      | Purposively sampled mothers. No further details on recruitment  | 4                   | Average     |
| Ncube 2016                            | To explore and describe the lived experiences of mothers with regard to the care of their hospitalised preterm infants, in a NICU where mothers had restricted interaction with their preterm infants | Botswana (upper-middle) | Dec 2010-Jan 2011     | Qualitative interviews (conducted in hospital whilst infant was admitted)<br>Thematic analysis                        | Neonatal unit                  | Purposive sampling from a NICU in a referral hospital; recruited by duty nurse who informed mothers of study  | 4                   | Good        |
| Neu 2020                              | To compare mothers' experiences in NICUs where family-centred care is the standard of care and to compare these with the experiences of mothers two decades ago                                       | USA (high)              | Not reported          | Qualitative interviews (conducted in hospital whilst infant was admitted)<br>Thematic analysis                        | Neonatal unit                  | Purposive sampling from two NICUs in teaching hospitals; no further details reported  | 4                   | Good        |
| Norén 2018                            | To describe mothers' experiences of providing their preterm infants with Kangaroo Mother Care   | Sweden (high)           | 2009                  | Qualitative interviews (conducted at the family home)<br>Content analysis   | Neonatal unit & community      | Consecutively recruited from two level 3 NICUs; no further details reported   | 4                   | Good        |
| Nyondo-Mipando 2020 & 2021 (2 papers) | To explore the experiences of caregivers in the implementation of Kangaroo Mother Care  | Malawi (low)            | April-June 2019       | Qualitative interviews and participant observation (in hospital whilst infant was admitted)<br>Thematic analysis      | KMC ward                       | Purposive sampling, recruited by researchers supported by nursing officers in four hospitals (one tertiary, three secondary)  | 3                   | Good        |
| Olsson 2017                           | To describe fathers' experiences of skin-to-skin contact with their premature infant  | Sweden (high)           | Jan 2014-June 2015    | Qualitative interviews (conducted in hospital [n = 19], or family home [n = 1])<br>Thematic content analysis          | Neonatal unit                  | Purposeful sample by designated nurses in the two neonatal units (one county, one university) to achieve maximum variation in demographics                                    | 4                   | Good        |
| Orapiriyakul 2007                     | To explore how mothers in Thailand develop maternal attachment to infants born preterm and requiring NICU hospitalisation   | Thailand (upper-middle) | June 2005-Aug 2006    | Qualitative interviews (location not reported) and participant observation (in NICU)<br>Constant comparative analysis | Neonatal unit                  | Three participants purposively sampled in two NICUs (one public university, one provincial hospital),   | 3                   | Good        |

(continued on next page)



Table 2 (continued)

| Author / Date                                  | Aim of study<br>(as reported in the papers)  | Country<br>(income)*         | Data<br>collection<br>dates | Methods  | Healthcare<br>setting of<br>interest                    | Recruitment method  | Data<br>richness<br>score | CASP<br>rating |
|--|--|------------------------------|-----------------------------|--|---|---|---------------------------|----------------|
| Petty 2018                                     | To gain insight into the post-discharge experiences of parents in relation to the adequacy of preparation for caring for extremely premature infants at home   | UK<br>(high)                 | Sept-Nov<br>2017            | Qualitative interviews<br>(conducted at the family<br>home)<br>Constant comparative<br>analysis  | Discharge<br>from NICU &<br>community                   | then subsequent<br>theoretical sampling<br>Purposive sampling via<br>the coordinator of an<br>NHS trust-based parent<br>support group   | 4                         | Good           |
| Petty 2019b<br>(2 papers)                      | To explore the narratives of parents to enable practitioners to understand what it is like to live through a period of neonatal care with their premature infant   | UK<br>(high)                 | Not<br>reported             | Qualitative interviews<br>(conducted at the family<br>home or a private<br>location)<br>Thematic analysis                              | Neonatal unit,<br>discharge<br>from NICU &<br>community | Purposive sampling;<br>volunteers were<br>requested through a key<br>gatekeeper linked to a<br>UK parent support<br>charity who<br>disseminated the<br>recruitment call<br>nationally using their<br>established email<br>contact database. | 4                         | Good           |
| Premji 2017                                    | To explore mothers' experiences of caring for their late preterm infants in the community  | Canada<br>(high)             | April 2013-<br>June 2014    | Qualitative interviews<br>(conducted at the family<br>home or a private<br>location)<br>Interpretative thematic<br>analysis            | Community   | Multistage purposeful<br>sampling to achieve<br>rich narratives and<br>diversity from four<br>hospitals in Calgary;<br>\$50 grocery gift card<br>incentive  | 3                         | Good           |
| Rossmann<br>2011                               | To describe the experiences of mothers of VLBW infants who received lactation care from certified breastfeeding peer counsellors with special preparation for NICU care  | USA<br>(high)                | Oct 2008-<br>Mar 2009       | Qualitative interviews<br>(conducted in hospital<br>whilst infant was<br>admitted)<br>Thematic content<br>analysis                     | Neonatal unit   | Convenience sampling,<br>approached by NICU<br>practitioner at a tertiary<br>care NICU  | 3                         | Good           |
| Russell 2014<br>& Sawyer<br>2013<br>(2 papers) | To explore parents' views and experiences of the care for their very premature infant on NICU (Russell 2014)<br>To explore parents' experiences and satisfaction with care during very preterm birth and to identify domains associated with positive and negative experiences of care (Sawyer 2013) | UK<br>(high)                 | June – Nov<br>2011          | Qualitative interviews<br>(conducted in hospital<br>or in the family home)<br>Inductive thematic<br>analysis                           | Neonatal unit   | Recruited from three<br>tertiary care centres in<br>England using posters<br>in NICU or posted/<br>personally-given letters;<br>parents returned a card<br>if they wanted to<br>participate   | 4                         | Good           |
| Skene 2012                                     | To explore how parents interact with their infants and nurses regarding the provision of comfort care in a NICU  | UK<br>(high)                 | Jan – Nov<br>2008           | Focussed ethnography,<br>with participant<br>observations and<br>qualitative interviews<br>(in NICU)<br>Inductive thematic<br>analysis | Neonatal unit   | Approached by<br>researcher in a regional<br>NICU   | 5                         | Good           |
| Treherne<br>2017                               | To discover parents' perceptions of closeness to and separation from their preterm infants in the NICU   | Canada<br>(high)             | Feb 2015 –<br>Jan 2016      | Qualitative data<br>collected through diary<br>voice app (for 24 h)<br>Thematic content<br>analysis                                    | Neonatal unit   | Purposive sampling in<br>an urban level III NICU,<br>with parents<br>approached by NICU<br>staff  | 4                         | Good           |
| Unsworth<br>2021                               | To explore caregiver experiences and healthcare provider perspectives of accessing healthcare for low birth weight infants in rural Kenya  | Kenya<br>(lower-<br>middle)  | June 2019                   | Qualitative interviews<br>(conducted within the<br>research area of the<br>hospital)<br>Thematic analysis                              | Community   | Convenience sampling<br>from neonatal and<br>postnatal ward registers<br>at a county hospital or<br>those known to<br>community health<br>volunteers; contacted<br>by telephone or home<br>visits   | 4                         | Good           |
| Veronez 2017                                   | To describe the maternal care process mediated by nurses during the period of hospitalisation and discharge of premature infants   | Brazil<br>(upper-<br>middle) | Oct-Dec<br>2011             | Daily journal written by<br>mothers<br>Thematic content<br>analysis  | Neonatal unit   | Recruited from<br>neonatal units by<br>researcher who was a<br>member of nursing staff  | 3                         | Good           |
| Villeneuve<br>2018                             | To identify outcomes that were important to families of  | UK<br>(high)                 | 2016–2017                   | Qualitative interviews<br>(conducted at a  | Neonatal unit   | Participants<br>purposively sampled   | 5                         | Good           |

(continued on next page)

Table 2 (continued)

| Author / Date | Aim of study (as reported in the papers)   | Country (income)*     | Data collection dates | Methods   | Healthcare setting of interest | Recruitment method   | Data richness score | CASP rating |
|---------------|--|-----------------------|-----------------------|---|--------------------------------|--|---------------------|-------------|
|               | children requiring neonatal care   |                       |                       | university, in the family home, or in a children's centre)<br>Thematic analysis |                                | from: lists held by neonatal support groups (BLISS, SNUG); conference on neonatal services; families known to NICU at Royal Devon and Exeter NHS Trust |                     |             |
| Wernet 2015   | To analyse the maternal experience in a neonatal intensive care unit, focusing on relations of recognition | Brazil (upper-middle) | May – August 2013     | Qualitative interviews (location not reported)<br>Thematic analysis             | Neonatal unit                  | Mothers recruited if preterm neonates had left the regional NICU less than one month prior to the interview; no further detail given on recruitment    | 4                   | Good        |
| Yu 2020       | To explore Chinese parents' experiences and expectations of having preterm infants in a Chinese NICU       | China (upper-middle)  | Jan – May 2018        | Qualitative interviews (conducted in hospital)<br>Thematic analysis             | Neonatal unit                  | Purposively sampled by first author from a NICU in a tertiary hospital   | 3                   | Good        |

Abbreviations: CASP = Critical Appraisal Skills Programme; NICU = Neonatal Intensive Care Unit; NHS = National Health Service; SCBU = Special Care Baby Unit; VLBW =

very low birthweight

\* According to the World Bank's income classification 2021–2022 (<https://datatopics.worldbank.org/world-development-indicators/the-world-by-income-and-region.html>)

descriptive themes, 21 of which we graded with high confidence, nine with moderate confidence, and one with low confidence using the GRADE-CERQual approach. Table 4 shows the framework of themes, associated CERQual gradings and supporting data. The full GRADE-CERQual evidence profiles for each descriptive theme are presented in Supplementary Tables A.1–A.8.

What mattered to carers was a positive outcome for the child; active involvement in care; support to cope at home after discharge; emotional support for the family; the healthcare environment; information needs were met; logistical support was available; and positive relationships with staff.

We now discuss these eight analytical themes in more detail. The themes are listed in alphabetical order to avoid undue emphasis being placed on one over another because of the review team's biases. Text identifying the descriptive themes within each analytical theme has been italicized.

### 3.3.1. A positive outcome for the child

Carers expressed a clear desire for positive clinical and social outcomes for their infant (with high confidence in the findings for this theme). These wishes were often reflected as a reframing of priorities in what mattered, particularly in relation to the infant attaining typical development goals. The main outcome hoped for was the infant's survival, but families also wanted positive clinical outcomes such as weight gain. They discussed their wishes for the child to come home and be a member of the family or community. Hopes for their child beyond childhood into adolescence or adulthood were rarely mentioned. Instead, parents focussed on short term outcomes, perhaps reflecting their need to concentrate on their immediate situation.

### 3.3.2. Active involvement in care

Carers wanted to be taught, be involved in, and have confidence in their ability to deliver essential care (such as nappy changes, pain management, supporting nutrition) to their vulnerable infant. In addition, carers wanted to be supported to be involved in activities other than essential care which encouraged opportunities for parenting, including bonding (for example, touching and cuddling), and social family activities (for example, singing or reading). Parents discussed the importance of kangaroo mother care, or skin to skin care, as both an opportunity to deliver

care and as an opportunity for parenting. These themes were ubiquitous across all settings (high confidence).

We had moderate confidence in the other descriptive themes in this group. *Fathers wanted to be directly involved in the routine care of their infant, and to be supported to do this.* However, they sometimes felt that they were not encouraged and not as welcome in the neonatal unit. It was not clear whether fathers had been asked for their views, or were willing and able to express these, in different locations and across different cultural groups. Carers also *wanted support and processes to help them engage and take an active part in deciding what, and when, investigations, treatments, interventions and discharge occur*, although findings varied between settings with different cultural expectations and legal responsibilities.

### 3.3.3. Coping at home

Carers wanted to be able to *access support and advice urgently* should they need it once the infant was discharged. Sometimes carers felt torn between the *desire for autonomy* from continual observation and input from healthcare professionals (HCPs), and the pressure resulting from this freedom as they became the primary carer for their child. Because of this conflict, we had moderate confidence in this finding. The importance of *wider family and community support* (for practical arrangements and advice) was clear. *Expertise from HCPs in the community* was also valued, although professional support in the community was described as inconsistent.

Carers *wanted to be prepared for their infant's discharge home.* This included being taught how to look after their infant and gradually developing their experience in delivering practical care. Carers also discussed the value of preparation for discharge in emotional terms, such as the need to build their confidence after a long stay in a medical environment. Although fewer studies contributed to these descriptive themes, we had high confidence in these findings due to consistency between studies.

Lastly, many parents *valued transition arrangements* which they felt helped facilitate the safe transfer of care. This included the delivery of information, planned care pathways, and home visits, to ensure continuity of care. We had moderate confidence in this finding because the complexity and duration of transitional arrangements varied greatly between settings. There were no studies from low or middle-income

**Table 3**  
 Characteristics of the study populations in sampled studies (n = 54).

| Author / Date   | Inclusion/exclusion criteria  | Sample size  | Patient population | Gestational age range at birth | Birthweight range              | Age of child at data collection                     | Other information  |
|-----------------|---|--|--------------------|--------------------------------|--------------------------------|---|--|
| Abeasi 2020     | <b>Included:</b> Mothers who had delivered an infant at < 37 weeks; infant had been in the hospital for > 5 days; infant's condition had improved if the infant had been very ill; and mother was not too anxious for an interview  | 12   | Preterm and/or LBW | 30–35 weeks                    | 1800–2200 g                    | Not reported  | Women aged 20–36; all had completed secondary (n = 7) or tertiary (n = 5) education                      |
| Adama 2017      | <b>Included:</b> Fathers who were aged 18 + ; their preterm infants had no disabilities   | 9 (interviewed 3 times)                            | Preterm            | 26–36 weeks                    | Not reported                   | Not reported  | Men aged 20–38; all in full time employment  |
| Adcock 2021     | <b>Included:</b> Mothers, fathers, and others in family collective of infants < 37 weeks  | 26 (19 mothers, 5 fathers, 1 aunt, 1 grand-mother) | Preterm            | < 28 – 37 weeks                | Not reported                   | 7 days to 15 months                                 | Not reported   |
| Amorim 2019     | <b>Included:</b> Parents whose very preterm infants survived; who were present in NICU during the hospitalisation period; able to speak and write in Portuguese; infant discharged and alive  | 52 (26 couples)                                    | Preterm and/or LBW | < 28 weeks                     | Not reported                   | Not reported  | Not reported   |
| Arnold 2013     | <b>Included:</b> Parents who could speak fluent English and had a preterm baby born prior to 32 weeks gestation in a 6-month period (Jan–June 2011)   | 39 (32 mothers, 7 fathers)                         | Preterm            | 24–31 weeks                    | Not reported                   | 44 – 344 days                                       | Parents aged 25–44; 29 of 39 were White European; 37 were married or cohabiting                          |
| Aydon 2018      | <b>Included:</b> Parents with babies admitted to the neonatal clinical care unit whose gestation was between 28 and 32 weeks<br><b>Excluded:</b> Parents with babies born with anomalies and/or not expected to survive; non-English speaking; or potentially difficult to follow-up due to involvement with the child and family protection services | 40 (20 couples, interviewed separately)            | Preterm            | 28–32 weeks                    | Not reported                   | 4–6 weeks old and 4–6 weeks post-discharge          | Mothers aged 21–42; fathers aged 21–43; 33 of 40 were first-time parents; 17 of 20 couples were married  |
| Blomqvist 2012  | <b>Included:</b> Fathers of an infant born at 28–33 weeks; infants did not have a life-threatening condition  | 7  | Preterm and/or LBW | 29–33 weeks                    | 1315–2500 g                    | 4 months + /- 2 weeks (corrected age)               | Fathers aged 25–36; all first-time fathers; all married or co-habiting with mother                       |
| Brødsgaard 2015 | <b>Included:</b> Parents who had participated in the Early Discharge Programme; infant born Jan - June 2012; gestational age 25–36 weeks; singleton or twins, first-time and experienced parents; able to understand and speak Danish well enough to participate actively in group discussions  | 15 (2 focus groups)                                | Preterm            | 28–34 weeks                    | 1230–2800 g                    | Approximately 6 months old                          | Mothers aged 29–39; fathers aged 34–42   |
| Chang Lee 2009  | <b>Included:</b> Mothers of infants whose birth weight was < 1500 g, and who were Taiwanese<br><b>Excluded:</b> Single mothers; teenage mothers (aged < 20); foreign mothers; mothers not physically or mental fit to be interviewed; multiple births; and infants with life-limiting illness or congenital abnormalities                             | 26   | Preterm and/or LBW | 25–34 weeks                    | 530–1490 g                     | Not reported  | Mothers aged 22–36   |
| Dorner 2020     | <b>Included:</b> English-speaking parents of infants born preterm who, at the time of interview: (1) were between 28 and 34 weeks' corrected age, and (2) had not yet been screened with General Movements Assessment examinations  | 19 (15 mothers, 4 fathers)                         | Preterm            | Median 29.6 (IQR 25.7 – 31.2)  | Median 1175 g (IQR 740–1735 g) | Not reported, although may be ~ 4 weeks after birth | Median age of parents 32 (IQR 27–38); 14 of 19 had been in higher education; 11 of 19 first-time parents |

(continued on next page)

Table 3 (continued)

| Author / Date          | Inclusion/exclusion criteria  | Sample size                 | Patient population | Gestational age range at birth                                | Birthweight range      | Age of child at data collection                      | Other information   |
|------------------------|---|-----------------------------|--------------------|---|------------------------|--|---|
| dos Santos 2014        | <b>Included:</b> Mothers of preterm infants, born at < 32 weeks and/or weighing < 1500 g; admitted to the NICU of the University Hospital of Londrina; who participated in the project "A support network for the premature infant's family"  | 21                          | Preterm and/or LBW | Range not reported  | Range not reported     | Up to 6 months (chronological age)                   | Mothers aged 14–42; 50% married; 60% had other children and < 8 years of education  |
| Feeley 2013            | <b>Included:</b> Infant's biological father; lived with infant's mother; infant had been hospitalised for 7 + days; infant's medical condition was stable; could communicate in English or French<br><b>Excluded:</b> Fathers with a previous experience of NICU; infants with grade 3–4 intraventricular haemorrhage or major congenital anomaly | 18                          | Preterm            | Mean 28 <sup>+6</sup> weeks                                   | Mean 1173 g            | Mean age 55 days                                     | Mean age of fathers 37.7; 8 of 18 has university education; all were currently employed   |
| Fernandez Medina 2021  | <b>Included:</b> Parents > 18 years old; with an extremely preterm infant who had been discharged from NICU with some type of technological dependency during the last 24 months<br><b>Excluded:</b> Parents of infants with a congenital disease   | 17 (12 mothers, 5 fathers)  | Preterm            | 24–27 weeks   | Not reported           | Not reported; infants discharged in last 24 months   | Mean age of parents 34.2; 12 of 17 were married;  |
| Finlayson 2014         | <b>Included:</b> English-speaking mothers; > 16 years; infant treated on the unit for 7 days or more<br><b>Excluded:</b> Mothers whose infants were receiving intensive care at the time of interview   | 12                          | Preterm and/or LBW | 25–31 weeks   | 595–1517 g             | Not reported   | Mothers aged 21–40; 11 of 12 identified as White-British; 6 of 12 university educated; all had partners   |
| Franck 2017            | <b>Included:</b> Parents whose babies had received NICU care within the past 3 years  | 40 (33 mothers, 7 fathers)  | Preterm            | Not reported  | Not reported           | Not reported; NICU care was received in past 3 years | 47% of participants were aged > 35 & 45% were aged 26–35; 85% were married; 90% were employed   |
| Gallegos-Martinez 2013 | <b>Included:</b> Parents with a preterm baby hospitalized in the neonatal unit  | 31 (9 mothers, 11 couples)  | Preterm            | Not reported  | Not reported           | Not reported   | 70% "nuclear" families; 89% of mothers "homemakers"; 82% of fathers were labourers; high school completion < 35%                                      |
| Glazer 2021            | <b>Included:</b> Mothers with a live birth between June 2016–June 2018; very preterm or very low birthweight (<1500 g) delivery with a minimum five-day NICU stay   | 20                          | Preterm and/or LBW | "Very preterm"  | "Very low birthweight" | Not reported   | 40% Black, 40% White or Asian, 20% Latina; 8 of 12 Black or Latina participants has Medicaid cover, all White or Asian participants privately insured |
| Granrud 2014           | <b>Included:</b> Parents of a premature baby born at a university hospital and transferred to a local hospital; able to speak Norwegian<br><b>Excluded:</b> prior experiences of preterm delivery   | 20 (2 mothers, 9 couples)   | Preterm            | 26–32 weeks   | Not reported           | Not reported   | Mothers aged 22–40, fathers aged 23–40  |
| Guillaume 2013         | <b>Included:</b> Parents who spoke French; whose child was born before 32 weeks of gestation; was 15–30 days old at inclusion; and had no recent severe clinical aggravation  | 60 (30 mothers, 30 fathers) | Preterm            | Mean 27 <sup>+2</sup> weeks<br>Maximum 31 <sup>+6</sup> weeks | Mean 956 g             | 15–30 days old                                       | Mothers mean age 30.7, fathers mean age 33.5; 92% employed; 8% single parents   |
| Gungdogdu 2022         | <b>Included:</b> a) being parent of a preterm baby, b) not have a hearing or speech impairment, c) parents' first NICU experiences  | 15 (11 mothers, 4 fathers)  | Preterm            | 22–37   | Not reported           | Not reported   | Parents mean age 27.33, income level of all parents was moderate, infants' hospitalisation range from 1 to 97 days                                    |
| Hägi-Petersen 2021     | <b>Included:</b> Parents from two neonatal wards offering early in-home care programmes with  | 11 (1 mother, 5 couples)    | Preterm            | 27–35 weeks   | Not reported           | Not reported; 14–30 days after discharge             | Mothers aged 21–41, fathers aged 24–38  |

(continued on next page)

Table 3 (continued)

| Author / Date    | Inclusion/exclusion criteria  | Sample size                            | Patient population | Gestational age range at birth | Birthweight range                    | Age of child at data collection       | Other information   |
|------------------|---|--|--------------------|--------------------------------|--------------------------------------|---------------------------------------|---|
|                  | nurse-supported video consultations (programme had inclusion criteria not specified in the paper)   |  |                    |                                |                                      | from in-home care programme           |   |
| Hendriks 2017    | <b>Included:</b> Parents of infants born alive at < 28 weeks and died in the delivery room or in the NICU from 2013 through 2015<br><b>Excluded:</b> Participants who gave birth to two or more infants; or if infants were stillborn                                       | 20<br>(5 mothers, 1 father, 7 couples) | Preterm            | 22–27 weeks                    | 340–1100 g                           | 1–2 years after the infant's death    | 14 of 20 aged 35 + ; 18 of 20 Christian   |
| Hua 2021         | <b>Included:</b> parents of infants born < 37 weeks who had been in NICU > 3 days.<br><b>Excluded:</b> parents requesting discharge against medical advice and those not the primary caregiver of the infant.   | 17 parents (8 mothers, 9 fathers)      | Preterm            | Not reported                   | Not reported                         | Not reported                          | 11 were first time parents, 6 were second time parents  |
| Ignell Modé 2014 | <b>Included:</b> Fathers of infants treated at one of two Swedish NICUs; able to speak Swedish. Infant inclusion criteria were absence of an acute life-threatening condition and a stay of at least 1 week in NICU   | 8                                      | Preterm            | 23–36 weeks                    | Not reported                         | Not reported                          | Fathers aged 20–24 years  |
| Jantsch 2021     | <b>Included:</b> Mothers of preterm infants born May 2016 - May 2018; who lived in the city of Santa Maria; who developed chronic and acute health conditions   | 15                                     | Preterm            | 32–36 weeks                    | Not reported                         | 3–9 months                            | 11 of 15 in socio-economic classes C or D; 6 of 15 infants had chronic health problems  |
| Kim 2020         | <b>Included:</b> Mothers of infants born < 37 weeks or LBW < 2500 g; if admission lasted at least seven days; and if infants did not have congenital anomalies and did not require life-prolonging treatment  | 232                                    | Preterm and/or LBW | Mean 30 <sup>+3</sup> weeks    | Mean 1523 g                          | Up to 18 months                       | Mothers mean age 34.19; 99% married; 99% with high school education or above  |
| Klawetter 2019   | <b>Included:</b> English-speaking mothers of infants born at < 32 weeks; hospitalised in NICU 2 + weeks; 33–34 weeks at the time of interview<br><b>Excluded:</b> Mothers < 18 years; with a diagnosed psychiatric disorder and/or recorded or stated illicit substance use | 14                                     | Preterm            | Maximum 31 <sup>+6</sup> weeks | Not reported                         | 33–34 weeks corrected gestational age | 9 of 14 mothers were White, 3 African-American; 7 of 14 had Medicaid cover; 13 educated to high-school level or higher; 11 were married |
| Leonard 2008     | <b>Included:</b> Parents of preterm infants receiving kangaroo care at the hospital at the time of the interview; able to speak English; singleton births; > 7 days old; weight > 1000 g; not receiving critical care (intubation and/or life support)                      | 6<br>(4 mothers, 2 fathers)            | Preterm            | Not reported                   | Minimum 1000 g; maximum not reported | Not reported                          | 5 married or co-habiting, 1 single mother   |
| Lian 2020        | <b>Included:</b> Fathers with full custody of their infants<br><b>Excluded:</b> Fathers whose infants died during the NICU stay; were unable to give informed consent; or unable to comprehend interview questions in English   | 15                                     | Preterm and/or LBW | 25–34 weeks                    | 580–1474 g                           | Not reported                          | 9 of 15 aged 31–40; all married; 10 of 15 educated at degree level; 13 of 15 employed full-time   |
| Liu 2019         | <b>Included:</b> Parents visiting their infant; able to speak and read English or French; aged > 18; infants hospitalised for 48 + hours<br><b>Excluded:</b> Infants with grade 4 intraventricular haemorrhage, trisomy 21 or other chromosomal abnormalities, in           | 15<br>(9 mothers, 6 fathers)           | Preterm            | 24–35 weeks                    | 620–3605 g                           | 5–108 days                            | Mothers mean age 34.6; fathers mean age 35; all married or cohabiting; 14 of 15 had college or degree education; 4 of 14 unemployed     |

(continued on next page)

Table 3 (continued)

| Author / Date       | Inclusion/exclusion criteria  | Sample size   | Patient population | Gestational age range at birth       | Birthweight range | Age of child at data collection                  | Other information   |
|---------------------|---|---|--------------------|--------------------------------------|-------------------|--|---|
| Lomotey 2020        | palliative care, and/or was being placed in foster care<br><b>Included:</b> Mothers with babies born < 37 weeks<br><b>Excluded:</b> Mothers whose preterm babies were critically ill or had congenital anomalies  | 10  | Preterm            | 26–36 weeks                          | Not reported      | Not reported                                     | Mothers aged 17–38 years; all educated to junior high school level; 9 were Christian; all married or cohabiting                                   |
| Lorié 2021          | <b>Included:</b> Parents of preterm infants (born < 37 weeks' gestation); admitted to a Dutch level 2–4 NICU for 1 + week; able to speak Dutch  | 20 (19 mothers, 1 father)                                   | Preterm            | 24–35 weeks                          | Not reported      | 1–5 years  | Parents aged 28–38 years; living across the Netherlands; used 12 different NICUs  |
| Lundqvist 2019      | <b>Included:</b> Parents of infants born < 37 weeks; who had ended the care period in hospital-based neonatal home care; able to communicate in Swedish or English  | 12 (6 couples)  | Preterm            | 26–36 weeks                          | 655–3200 g        | Not reported                                     | Mothers aged 30–40, fathers aged 32–43; 3 couples from urban and 3 from rural area  |
| Merritt 2022        | <b>Included:</b> fathers having a premature infant born between 23-< 37 weeks; infant had been a patient in NICU with no congenital anomalies; and had been discharged 2 weeks or longer.   | 28 fathers  | Preterm            | Mean 29.32 weeks (range 24–36 weeks) | Not reported      | 1 week to 16 years                               | Length of NICU hospitalisation ranged from 3 to 122 days (mean 61.85)   |
| Mihae 2021          | <b>Included:</b> Mothers who understood the purpose of the study and agreed to participate; with infants born < 37 weeks; without congenital deformities and hereditary diseases; and within a year of childbirth   | 10  | Preterm and/or LBW | 24–34 weeks                          | 655–2000 g        | 1–10 months                                      | Mothers aged 22–43; all married; 7 of 10 first-time mothers   |
| Namusoke 2021       | <b>Included:</b> mothers who had delivered live babies < 37 weeks and admitted to NICU<br><b>Excluded:</b> Mothers who neonates were very ill or had congenital abnormality, or were unable to communication in local language or English.  | 51 mothers (16 in interviews, 35 in focus groups)           | Preterm            | 23–37 weeks                          | Not reported      | All mothers in Focus Groups had babies < 3months | Mothers who participated in interviews were excluded from focus groups.   |
| Ncube 2016          | <b>Included:</b> Mothers of singleton infants born < 37 weeks; hospitalised for 5 + days but with stable or improving health; able to speak Setswana or English<br><b>Excluded:</b> Mothers of infants acutely ill at the time of data collection; or whose infant had a congenital abnormality | 8   | Preterm            | Not reported                         | Not reported      | Not reported                                     | Mothers aged 23–30  |
| Neu 2020            | <b>Included:</b> Mothers of infants born < 32 weeks; at least 33 weeks postconceptional age; hospitalized for 2 + weeks<br><b>Excluded:</b> Mothers diagnosed with a psychiatric disorder such as bipolar disorder or schizophrenia and/or recorded or stated illicit substance use             | 14  | Preterm            | < 32 weeks                           | Not reported      | At least 33 weeks corrected age                  | Mothers mean age 28; 9 of 14 White, 3 of 14 Black or African American; 10 had college or degree level education; 11 married; 10 working full-time |
| Norén 20108         | <b>Included:</b> Mothers of singleton infants born at 28–33 weeks; whose condition was not life-threatening; able to speak Swedish  | 13  | Preterm and/or LBW | 29–33 weeks                          | 1175–2500 g       | 4 months (+/- 2 weeks) corrected age             | Mothers aged 25–42; all married or cohabiting with father; 8 of 13 first-time mothers   |
| Nyondo-Mipando 2020 | <b>Included:</b> Caregivers of preterm or LBW infants who were in a stable condition; were providing KMC; and had been in the KMC ward for 5 + hours  | 24 (14 mothers, 6 fathers, 3 grand-mothers, 1 grand-father) | Preterm and/or LBW | Not reported                         | < 2500 g          | Not reported                                     | Not reported  |
| Olsson 2017         | <b>Included:</b> Fathers of preterm infants; who had provided skin-to-skin care to the infant at least once   | 20  | Preterm            | 25–35 weeks                          | Not reported      | 2–74 days old                                    | Fathers aged 23–45  |

(continued on next page)



Table 3 (continued)

| Author / Date             | Inclusion/exclusion criteria  | Sample size                          | Patient population | Gestational age range at birth | Birthweight range | Age of child at data collection                               | Other information  |
|---------------------------|---|--------------------------------------|--------------------|--------------------------------|-------------------|---|--|
| Orapiriyakul 2007         | <b>Included:</b> Thai mothers; living with partners/ husbands; with preterm infants < 37 weeks by Ballard scores assessment; birth weight < 1500 g; no congenital anomaly; requiring mechanical ventilation and hospitalized in NICU  | 15                                   | Preterm and/or LBW | 26–33 weeks                    | 740–1400 g        | 2–33 days   | Mothers aged 16–41; 12 of 15 were Buddhists; 5 of 15 educated to diploma or degree level; 12 reported low family income        |
| Petty 2018                | <b>Included:</b> Parents whose infants were born at < =30 weeks; who had been discharge home within the previous one to six years   | 15 (12 mothers, 1 father, 1 couple)  | Preterm and/or LBW | 24–30 weeks                    | 615–1600 g        | 1–6 years   | Parent characteristics not reported  |
| Petty 2019b (2 papers)    | <b>Included:</b> Parents whose infants were born at < 37 weeks; had spent more than a week receiving neonatal care; and who had been discharged home in the preceding ten years   | 23 (16 mothers, 1 father, 3 couples) | Preterm and/or LBW | 24–32 weeks                    | 500–1500 g        | 1–10 years  | Parent characteristics not reported  |
| Premji 2017               | <b>Included:</b> Mothers of late preterm infants regardless of mode of delivery and admission status (newborn nursery, secondary hospital or NICU, or length of stay)<br><b>Excluded:</b> Mothers unable to read/write English; or could not be contacted in time for them to complete the maternal confidence in care survey | 11                                   | Preterm            | 34–36 weeks                    | 1822–3630 g       | Not reported  | Mothers mean age 31.1; all married; 6 of 10 had completed higher education; 8 of 10 born in Canada; 6 of 10 White              |
| Rossman 2011              | <b>Included:</b> Mothers of a VLBW infant in the NICU who was expected to survive; maternal age 18 + years; able to speak and understand English; 3 + interactions with a breastfeeding peer counsellor   | 21                                   | Preterm and/or LBW | 24–31 weeks                    | 511–1460 g        | 12–80 days  | Mothers mean age 29.3; 15 of 21 African-American; 11 of 21 married; 17 of 21 had some college education; 12 employed full-time |
| Russell 2014; Sawyer 2013 | <b>Included:</b> Parents whose infants were born at < 32 weeks (also birth < 6 months previously in Sawyer); had been on neonatal unit for 2 + weeks; spoke English well; at least one member of the couple wanted to participate or they were single; included parents of babies who had died                                | 39 (32 mothers, 7 fathers)           | Preterm            | 24–31 <sup>+6</sup> weeks      | Not reported      | 44–344 days (Russell); < 6 months (Sawyer); 2 babies had died | Parents aged 25–44; 37 of 39 married or co-habiting; 29 White European; 33 employed  |
| Skene 2012                | <b>Included:</b> Parents > 16 years; considered as suitable for inclusion by the nurse in charge  | 19 (2 mothers, 1 father, 8 couples)  | Preterm and/or LBW | 23–32 weeks                    | 520–1615 g        | 5–31 days at recruitment                                      | Majority of parents were White British   |
| Treherne 2017             | <b>Included:</b> Parents whose infants were born at < 37 weeks; hospitalised in the NICU; infant was stable; able to read English or French; able to provide informed consent   | 20 (13 mothers, 7 fathers)           | Preterm            | 24–33 weeks                    | 615–3030 g        | 8–94 days   | Mothers mean age 32.2; fathers mean age 37.3; 10 of 20 had university degrees; all in employment                               |
| Unsworth 2021             | <b>Included:</b> Caregivers of LBW infants < 24 months of age   | 11 (all female, roles not specified) | Low birth weight   | Not reported                   | Not reported      | < 24 months   | 9 of 11 caregivers aged > 25   |
| Veronez 2017              | <b>Included:</b> Mothers of infants born at < 37 weeks; birth weight more than 1500 g; hospitalisation time > =72 h; and residents of the municipality of Maringá or in the 15th health region  | 7                                    | Preterm and/or LBW | 31–36 weeks                    | 1560–2460 g       | Not reported  | Mothers aged 16–31   |
| Villeneuve 2018           | <b>Included:</b> Parents who had used a neonatal service and been discharge from the service within the last 6 months to 5 years  | 12 (8 mothers, 2 couples)            | Preterm            | 24–34 weeks                    | Not reported      | 6 months to 5 years post-discharge                            | For “half of the families”, this was their first child   |
| Wernet 2015               | <b>Included:</b> Mothers of infants born at < =34 weeks; without  | 10                                   | Preterm            | 26–34 weeks                    | Not reported      | Roughly aged up to 5 months                                   | 6 of 10 mothers aged 18–25, 3 aged 25–30, 1  |

(continued on next page)

Table 3 (continued)

| Author / Date | Inclusion/exclusion criteria  | Sample size                   | Patient population | Gestational age range at birth | Birthweight range | Age of child at data collection | Other information   |
|---------------|---|-------------------------------|--------------------|--------------------------------|-------------------|---------------------------------|---|
|               | any congenital syndromes; who stayed in the NICU for at least one week<br><b>Excluded:</b> Mothers who had another preterm child; those with any mental health problems   |                               |                    |                                |                   |                                 | over 40 years; 5 of 10 were first-time mothers; 7 of 10 lived with partners and 3 were single mothers                               |
| Yu 2020       | <b>Included:</b> Parents of a preterm infant; admitted to the NICU for 7 + days; infant's condition was stable; parents were aged 18 + ; and were the primary caregiver<br><b>Excluded:</b> History of mental illness; infants were abandoned or deceased | 15<br>(10 mothers, 5 fathers) | Preterm            | 27–36 weeks                    | 1010–2850 g       | Not reported                    | Mean age of parents 31.1 years; 11 of 15 were first-time parents; 8 of 15 had completed high school, 4 of 14 had completed a degree |

countries that contributed to this finding.

### 3.3.4. Emotional support for families

Carers wanted to have emotional support from any source (often healthcare workers); including reassurance and encouragement, to enhance their interactions and journey after the birth of a preterm or low birth weight infant. Specialist counsellors were valued for their ability to provide emotional support, particularly when parents were faced with bereavement or a poor prognosis for their infant. Fathers also valued emotional support, but often felt that they had to be emotionally strong to support the infant's mother (moderate confidence because few studies, especially from low and middle-income countries, explored the emotional support needs of fathers).

Family support, particularly from grandparents and siblings, was valued by parents. We also noted that carers valued support from parents of other preterm or sick infants who were considered helpful in providing information about the healthcare environment or sometimes in relation to the health condition of the infant. Perhaps more importantly, other parents were able to provide emotional support, hope and comfort.

### 3.3.5. Healthcare environment

Parents expressed strong views about the environment in which their infants were cared for, especially neonatal units. Carers wanted easy access to their infants. This included mechanisms or initiatives to help them to visit and interact with their infant and, where possible, the co-location of twins. Carers wanted to learn about the complex and sometimes frightening setting (in terms of noises, leads/equipment, and processes) in which they needed to live and care for their infant. They valued the ability to tour the NICU before the birth (for example, if a preterm or LBW birth was suspected in pregnancy). Carers were also concerned about real, or perceived, issues with staffing levels, equipment availability, and capability of the healthcare system to meet the needs of their infant.

Carers wanted privacy for breastfeeding or everyday family activities or interactions (for example, reading stories) in neonatal units. However, they also understood the need for medical observation, and struggled with the conflict between their desire for seclusion and for close monitoring by staff. This was the descriptive theme with the most conflicting views, and it was not mentioned in any studies from low or middle-income countries. We therefore have low confidence in this finding.

### 3.3.6. Information needs met

Carers described wanting a great deal of information relating to the infant's condition, prognosis, investigations and procedures performed, as well as routine information about the infant's daily events. However, they also felt overloaded. There was a tension between wanting to be told about all possible eventualities, and only wanting to know what they needed to know at any particular point in time. Due to this conflict,

we had moderate confidence in this finding. Carers also wanted frequent and regular updates from the clinical team (rather than just meetings when sentinel events occur) and open channels of communication.

Carers wanted HCPs to have good communication skills and to use a variety of information-giving methods. This related to a need for immediacy, an appropriate pace and timing of information-giving, and the opportunity for follow-up discussions. However, what constitutes good communication may vary by parent, culture, and situation. Although we had minor concerns about this variability, we graded this finding with high confidence because all carers agreed that they wanted clear and appropriate communication from HCPs. Carers also wanted to feel confident in obtaining information from multiple sources including from HCPs (for example, by being comfortable or enabled to ask questions) and supplementing this information via other trusted sources such as leaflets, books and the internet.

### 3.3.7. Logistical support

Carers wanted a range of practical and logistical support during the first two years of their infant's life. Perhaps most immediately, they needed practical support to travel to see their infant, and support to sleep and live near them during their inpatient stay. In addition, they wanted support for the wider family (for example, crèche facilities for siblings) to allow them to engage in their 'normal' parenting and caring roles, before and after discharge. In all settings, carers wanted additional support and recognition of the direct (for example, medical costs) and indirect (for example, travel or lost earnings) financial burdens, both while the infant was an inpatient and afterwards. Finally, parents wanted formal, protected leave to allow them to visit the infant whilst in hospital, and to support them to provide care for a prolonged period after birth. Given the large variation in employment practices and laws across settings, this finding was graded with moderate confidence.

### 3.3.8. Positive relationships with staff

Carers wanted to develop compassionate and sensitive relationships with the HCPs caring for their infant. They also wanted consistency in care and communication, so that they could better understand rules, advice, therapeutic plans and predictions of outcome from and between different HCPs. We have moderate confidence in this finding, as this was not discussed in studies from low and middle-income countries. Carers wanted HCPs to be well-trained, competent, and able to provide the specialist care needed by the infant. However, carers also desired the development of respectful, collaborative relationships with the HCP, where the parent was identified and heard as an important part of the care-team with unique skills and knowledge of the infant.

Table 4

Framework of themes generated from the data.

| Analytical theme                 | Descriptive theme (review finding)   | Studies contributing to review finding                                     | CERQual grading     | Supporting data  |
|----------------------------------|--|--|---------------------|--|
| A positive outcome for the child | <b>A positive outcome for the child:</b> Carers expressed a desire for a successful clinical and social outcome for their baby as they grow (as distinct from the process or interventions themselves).                                | 21 studies[33,37,38,44,46,49,50,54,55,57,59,61,62,64,66,69,71,74,77,78,85] | High confidence     | <p>“When I had a preterm child. I changed.it changed everything that I used to think was important.I used to think my baby should be beautiful.with big eyes, but now I only want my baby to grow healthily.” (country = Taiwan, study setting = hospital)[37]</p> <p>“I am just happy having this baby regardless of how he is. Babies die daily on this unit so I’m happy whenever I go and meet my baby alive.... some people even have babies with abnormalities yet they are happy. How much more me? Once I see him alive, I become happy and I pray he continues to live.” (Ghana, hospital)[57]</p>  |
| Active involvement in care       | <b>Delivering care:</b> Carers want to be taught, be involved in, and have confidence in their ability to deliver some of the essential care (such as nappy changes, pain management, supporting nutrition) to their vulnerable infant | 28 studies[30,32,35,37,40,42,44,48,54–57,59–63,66,70–72,74–78,80,81]       | High confidence     | <p>“What I appreciate about the nurses here [is that they] make you [become] autonomous [in] the good kind of way. [.] They don’t force you into it. First, they show you how to do it, and if you’re comfortable doing it, they’ll supervise you, but then after a while, they’ll let you go and fly on your own.” (Canada, hospital)[56]</p> <p>“I was afraid of him ... not knowing how I am going to handle him... There is a nurse who told me not to be afraid of him because it is me who is going to take care of him while they show us how to take care of them.” (Botswana, hospital)[61]</p>   |
|                                  | <b>Fathers involved:</b> Fathers want support to be directly involved in the routine care of their infant, alongside support and encouragement to do this  | 11 studies[31,35,40,44,47,54,55,59,64,65,73]                               | Moderate confidence | <p>“I went to the unit every evening after work to spend time with my child and wife but anytime I went there, I could not see and hold my baby for long. I felt like I was not welcome but I kept on asking questions. All the attention was given to the mother and I was left out.” (father, Ghana, hospital)[31]</p>   |
|                                  | <b>Opportunities for parenting:</b> Carers want to have support with activities to encourage bonding (including touching and cuddling), and social family activity which falls outside the need for essential care.                    | 26 studies[33,35,37,40,42,45–47,52–58,60–63,65,66,74,75,77,78,81]          | High confidence     | <p>“I asked the nurse if it was ok to have a cuddle and she said, “you should have been having at least one a day”, but at the start I didn’t realise you could ask them.” (UK, hospital)[42]</p> <p>“As I was performing kangaroo care, I felt like I was acting as a mother, and I felt proud that I was helping my baby and doing something for her.” (South Korea, hospital)[60]</p>   |
| Coping at home                   | <b>Shared decision making and consent:</b> Carers want support and processes to help them engage and take an active part in deciding what, and when, investigations, treatments, interventions and discharge occurs.                   | 10 studies[32,42,43,49,56,58,61,68,75,78]                                  | Moderate confidence | <p>“...care plans would be modified without any explanation.” (Canada, hospital)[56]</p> <p>“Our voice is important. our views must be taken on board.” (UK, hospital and community)[68]</p>   |
|                                  | <b>Accessing support in a crisis:</b> Carers want mechanism to find help and advice urgently after discharge home when the primary care is transferred to the family   | 10 studies[31,36,39,43,48,62,76,82,83,85]                                  | High confidence     | <p>“I think the biggest thing is just that worry of is everything going to be okay? Here he’s on the monitor all of the time so you’ve got that safety blanket that if something goes wrong, a) you’ll know about it and b) there’s people here that jump right in and help with it... So it’s like when I’m home and don’t have that am I going to miss something?” (USA, hospital)[62]</p> <p>“Sometimes it is raining and when the baby is unwell, there is no transport to get there very fast to get help. It is very difficult and sometimes if the baby was to be helped there is no means of getting there faster.” (Kenya, community)[76]</p> |
|                                  | <b>Autonomy:</b> Carers want to take over the responsibility as the primary, and often only caregiver and decision maker for the infant after discharge.   | 6 studies[36,48,54,59,69,70]   | Moderate confidence | <p>“I felt divided [in NICU], torn into two pieces, which were only assembled once I got home.” (Denmark, hospital and community)[36]</p> <p>“At home I didn’t have spectators ... I felt at peace and I could hold her and put her on me and it was beautiful.” (South Africa, hospital)[54]</p>  |
|                                  | <b>Extended family support/ community resources:</b> Carers want support in obtaining advice and care from the wider community, rather than the just from the health sector.   | 8 studies[32,36,41,43,48,76,78,85]   | High confidence     | <p>“We were very lucky because we have a great family. My oldest daughter was 21 months old, I couldn’t attend to her needs, and my mother-in-law had to step into a mother’s role with her, but there are many parents who are alone...” (Spain, community and out-patients) [41]</p> <p>“Back home when most people would see my baby, they would ask me ‘what is that you are carrying?’ and yet they very well know you are carrying a baby but they say it just to make you feel bad. But you have no option except to continue tolerating people and putting your</p>  |

(continued on next page)

Table 4 (continued)

| Analytical theme               | Descriptive theme (review finding)   | Studies contributing to review finding                                  | CERQual grading     | Supporting data   |
|--------------------------------|--|---|---------------------|---|
|                                |  |   |                     | <i>baby under the sun to work on the yellowing skin.</i> " (Uganda, community)[85]  |
|                                | <b>Healthcare professional (HCP) expertise in the community:</b> Carers want experienced, knowledgeable, and competent HCPs in the community to take over the health support for the ex-preterm and low birth weight infant.   | 8 studies[41,43,48,51,69,70,76,83]                                      | High confidence     | "We've mixed a little bit of the two things we've been recommended. we've taken 50% from the neonatal ward and 50% from the municipal health visitor, and then we made our own mix of what we think fits." (Denmark, community)[48]<br>"I would like to see better parent support from GPs, from consultants, from health visitors, a better understanding." (UK, hospital and community)[69]   |
|                                | <b>Preparation for discharge:</b> Carers want to be practicably prepared, with education and confidence in their increased delivery of care, alongside emotionally support, for the discharge from a healthcare setting to the home, often after a long stay in a medical environment.                               | 18 studies[31,36,39,43,48,52,58,59,66,69,70,76,77,79,80,82,83,85]       | High confidence     | "We learned everything we needed and knew what we had to do, I was quite comfortable when we went home." (Denmark, hospital and community)[36]<br>"I wish to receive education and training on the rehabilitation of preemies ... Also, I'd like to learn how to deal with expected situations about my baby after leaving the NICU." (South Korea, hospital)[52]   |
|                                | <b>Transition arrangements:</b> Carers want adequate and safe transfer of health care responsibilities to other community organisations and professionals as part of the discharge home. This includes the delivery of information, pathways of care, and home visits, in order to delivery safe continuity of care. | 5 studies[39,41,43,59,63]   | Moderate confidence | "My son came home with a nasogastric tube, there is a nurse in the hospital who is in charge of teaching you how the tube and the feeding pump work, but when you are at home the responsibility is entirely yours, the moment when the nasogastric tube goes outside is very complicated, and you can't be thinking as a parent whether you have put the tube in correctly or not, and if his lung is going to fill up with food... therefore, counting on a professional companion is very important." (Spain, hospital and community)[41]  |
| Emotional support for families | <b>Support for and from the wider family:</b> Carers want emotional support from, and for the wider family (including grandparents and siblings)   | 10 studies[37,40,44,54,55,64,66,70,78,81]                               | High confidence     | "I have my in-laws...they are always there, whether it be for moral or practical support." (Canada, hospital)[40]<br>"I have a lot of responsibilities. I think the first one is to help the mother is doing the kangaroo mother care. When she wants to rest, the baby is put on me and I do exactly what she does except breastfeeding. The second thing is to see her doing everything accordingly as told by the doctors... Also, I think it is my responsibility to encourage her that things are going to be ok." (Grandmother, Malawi, hospital)[64]<br>"Only direct siblings are allowed to see the babies. To me that's the white way of thinking, we're Māori." (New Zealand, hospital)[81] |
|                                | <b>Support for parents:</b> Parents want to have emotional support from any source (often healthcare workers); including reassurance and encouragement, to enhance their interactions and journey after the birth of a preterm or low birth weight infant. This may also include spiritual support.                  | 22 studies[32,38,41,43,46,47,50,52,54,56,58,60,61,66,69,71-74,77,80,81] | High confidence     | "She then comforted me and told me to focus on the now and forget about the past. She said we should focus on the positive side and hope that the baby will be well. I felt better after talking to that nurse." (Botswana, hospital)[61]<br>"I went into a bit of a depression... it was not postnatal depression as such, more the effect of everything... they were really supportive, got me some counselling, so that was good." (UK, hospital and community)[69]  |
|                                | <b>Support for fathers:</b> As above, but regarding emotional support specifically delivered to support the father of the infant.  | 8 studies[33,40,43,54,55,59,65,84]                                      | Moderate confidence | "I needed to be strong for her, because I knew that she was going through a hell of a lot. I was too ... but ... I think to balance all ... the emotions ... that I had to suppress it." (father, South Africa, hospital)[54]<br>"We think we can shoulder everything and not have it affect us. Fathers need a voice of what they are feeling for real without being called weak; you know what I am saying?" (USA, hospital)[84]  |
|                                | <b>Support from other parents in similar situation:</b> Carers wanted support from other parents of preterm or sick infants; to develop their interactions and support the journey after a preterm or low birthweight birth.   | 17 studies[32,37,41,43,48,53-55,57,61-63,69,71,76,78,80]                | High confidence     | "The fact that they did walk in my shoes and they've been through some of the exact things that I was going through. made your experience of going through this a little easier to bear." (USA, hospital)[71]<br>"... there were also many mothers who had small babies, I was not alone. We were around five and we encouraged each other so that we could be strong for our babies that they may live and that whatever the people were saying could not happen." (Kenya, community)[76]  |
| Healthcare environment         | <b>Access to babies:</b> Carers want mechanisms, or initiatives, to help them to visit and interact with their baby (including specific issues with the co-location of twins)  | 16 studies[30,33,37,40,44-46,52,54,57,59,63,66,72,80,81]                | High confidence     | "You cannot just touch your baby when you want to, you have to be given the go ahead from the staff." (Nigeria, hospital)[30]<br>"I saw him just a moment, how small he was. After  |

(continued on next page)

Table 4 (continued)

| Analytical theme      | Descriptive theme (review finding)  | Studies contributing to review finding                               | CERQual grading     | Supporting data   |
|-----------------------|---|--|---------------------|---|
|                       |   |  |                     | delivering he was moved to the other room... Then I did not see him until next morning... I was anxious and worried about him." (Thailand, hospital)[66]<br>"Yeah [my breasts are] good, 'cause I milk them a whole lot, and babies feeding now, and I have a room here now so I can stay, I can stay with baby and do night feeds." (New Zealand, hospital)[81]  |
|                       | <b>Orientation and familiarity with NICU:</b> Carers want to learn about the healthcare setting (e.g. the noises, leads/equipment, and processes) in which they need to live and care for their infant (including the ability to tour the NICU before the birth if practical).  | 20 studies[30,33,37,40,42,45,47,50,53,54,60–63,65,66,75,77,78,81]    | High confidence     | "I'm glad they [showed me around], because it's quite daunting going into intensive care, NICU. I've never been in. All the, you know, computers, mechanical wombs basically for the premature babies. I'd never seen a premature baby previously. So it gave me an insight of what it would freak me out if I'd just gone up there after having the babies. At least I knew where they were going." (UK, hospital)[33]<br>"When I walked into this big room with all the incubators and all the other critically-ill little babies, I couldn't focus on just mine. There were so many machines sending out loud beeps. As I walked closer to the corner where they kept my baby, I nearly collapsed. He had so many lines and tubes attached to his tiny body. it was terrible. I just wanted to run away." (Taiwan, hospital)[37] |
|                       | <b>Privacy vs monitoring:</b> Carers want privacy for them and their families for breastfeeding or everyday family activities (e.g. reading stories) in neonatal units. However, they also understand the need for medical observation and monitoring, and therefore struggle with the potential conflict between desire for privacy and desire for monitoring. This theme also included parental views on the structure and design of neonatal units (e.g. large wards versus individual rooms). | 6 studies[40,53,56,62,74,75]   | Low confidence      | "Even when we pumped milk, we didn't need a curtain to hide behind, there aren't many people, we are alone, and we are free to pump milk without embarrassment, without people seeing us." (Canada, hospital)[56]<br>"I like the open pod because I can see other mothers. It is easy to meet them and talk. The nurses can see the babies all the time." (USA, hospital)[62]   |
|                       | <b>Staffing and equipment levels:</b> Carers are concerned about real, or perceived, issues with staffing levels, equipment availability, and seeing to the needs of the infant.  | 10 studies[32,33,37,43,46,52,56,61,72,76]                            | High confidence     | "I often feel there is a shortage of medical staff working in the NICU. It may be or must be too hard for one nurse to care for several babies properly at once." (South Korea, hospital)[52]<br>"What made me sad is, you will find your baby there. not taken care of. If you happen not to go to the unit because you were not feeling well, by the time you go there to check on her, you will find her in the same sheets and the nappy not changed." (Botswana, hospital)[61]   |
| Information needs met | <b>Information about the baby:</b> Carers want information relating to the baby's condition, prognosis, investigations/procedures performed or daily events. However, they also can feel overloaded and there is often a conflict between wanting to be told about all possible information and outcomes, and only wanting to know what they need to know at that particular point in time.   | 20 studies[32,36,38,43,44,46,47,49,50,57,60,61,66,72,77,78,80,82–84] | Moderate confidence | "Mother: One day, I arrived at NICU and I saw the incubator empty. I was in shock. I didn't ask any question, I just started crying. When a nurse saw me [crying], she ran to tell me that my daughter was moved to be closer to her twin. She should have been more careful and call me (.) or to the father. This could seem the most insignificant thing in the world but it's not, it's very important [for us]." (Portugal, hospital)[32]<br>"Another thing was that some doctors tended to [exaggerate]...the baby's disease and it really scared us. They would...inform us about all the possible complications. I felt unsure about those issues. I did not know how to describe the feelings, especially when they [complications] did not happen to my baby." (China, hospital)[80]                                      |
|                       | <b>Frequent updates:</b> Carers want frequent and regular updates from the clinical team, rather than just meetings when sentinel events occur, alongside open channels of communication.   | 7 studies[35,50,54,62,72,77,78]                                      | Moderate confidence | "They do inform you every day. they keep you up to date. inform you of the progress of the infant, if there is something wrong with him or things like that, the sisters are quite clued up so they keep you clued up as well." (South Africa, hospital)[54]<br>"They ask you if you want to be in for the rounds every time and I'm like, 'of course I want to be in for the rounds.' They'll just open up the door and let you sit in." (USA, hospital)[62]   |
|                       | <b>How information is given:</b> Carers want HCPs to have good communication skills and to use a variety of information-giving methods. This relates to a need for immediacy, an appropriate pace and timing of information giving, and the opportunity for follow-up discussions. However, what constitutes good   | 9 studies[30,32,43,47,49,58,77,78,80]                                | High confidence     | "I try to read online, but most often because I am not a medical person, I do not understand and would have wished to get more information from the staff, especially the nurses. I believe the staff can explain things to me at my level by excluding all those big words." (Nigeria, hospital)[30]<br>"I mean, I knew it was busy but they still do not have the   |

(continued on next page)

Table 4 (continued)

| Analytical theme                  | Descriptive theme (review finding)   | Studies contributing to review finding                           | CERQual grading     | Supporting data  |
|-----------------------------------|--|--|---------------------|--|
|                                   | communication may vary by parent, culture and situation.   |  |                     | <i>right to drop heavy news just like that and then say 'oh, by the way, I don't have any time right now to talk about it but we will do so tomorrow'. Well, you just cannot do that and, for me, that was really like. I don't want to talk to you anymore."</i> (Netherlands, hospital)[58]  |
|                                   | <b>Matching needs with information.</b> Carers want their informational needs and expectations to be met, and to feel confident in obtaining that information (e.g. by being comfortable or enabled to ask question). They also want to supplement this information via other sources (e.g. leaflets, books and the internet). | 19 studies[30,36,37,42,43, 45,47,49,50,52,53,55–58, 72,78,80,81] | High confidence     | <i>"And they said, 'you don't need to concern yourself with that, we need to concern ourselves with that'. And I was like, actually I don't agree, I think I need to know that as well cos I'm his mum."</i> (UK, hospital)[42]<br><i>"I think it has been very clear. and good. There is a lot of information all the time, but not so much that I need to ask more questions afterwards. Most of what I am wondering about is covered."</i> (Sweden, hospital)[50]   |
| Logistical support                | <b>Accommodation (comfort and facilities):</b> Carers need practical support in travelling to see their infants, and support to sleep and live near them during their initial inpatient stay.  | 14 studies[32,35,43,45,46, 53,54,56,57,62,63,72,78, 84]          | High confidence     | <i>"Those beds were anything but what you would call a bed, perhaps you know what they look like. They are like sofa beds they are hideous. I don't think I have ever had such a pain in my back after sleeping in a bed before, but, all you could do was to endure."</i> (Sweden, hospital) [35]<br><i>"I've found even if you have money to get up here, the food is really expensive and you only have \$5 left. The [bus] fare is \$5 minimum, so it's like should I eat or have money to get home? So, you're like okay I need to get home, so you don't end up eating and you're starving."</i> (USA, hospital)[53] |
|                                   | <b>Broader family support and impact:</b> Carers want support for the wider family (such as creche facilities for siblings) to allow the carers to engage in their 'normal' parenting and caring roles, before, and after, discharge   | 14 studies[40,44,48,53,54, 59,61,62,64,65,76–78,81]              | High confidence     | <i>"Trying to manage everything together has an impact. Work, come home, do laundry, clean the house, take care of my son, go to the internet, work, wake up. It's just a continuous cycle."</i> (father, Canada, hospital)[40]<br><i>"Every day I have more hope that he'll leave soon. His little sister is at home, she's anxious to meet the brother who was born, but has still not come home."</i> (Brazil, hospital)[77]  |
|                                   | <b>Costs of treatment:</b> Carers want additional support, or recognition, of the direct and indirect costs (e.g. travel) needed while the infant is an inpatient, and then afterwards for additional appointments and lost earnings because of the preterm birth.   | 14 studies[30,32,41,43,44, 53,57,60,64,69,76,78,84, 85]          | High confidence     | <i>"The doctors said my child has another condition, so I buy a lot of drugs which are very expensive. I have seen people lose their babies after all the money spent, I just pray mine gets well."</i> (Nigeria, hospital)[30]<br><i>"I had to leave my job to take care of him, I couldn't miss work an average of twice a week for medical appointments. We had to tighten our belts a lot, if you don't have savings or family who can help you financially it is extremely complicated. We had to move to my parents' house because we had no money."</i> (Spain, hospital and community)[41]                         |
|                                   | <b>Parental leave:</b> Parents want formal, protected leave to allow them to visit the baby whilst in hospital, and to support them to provide care for a prolonged period after birth.  | 8 studies[32,41,53,59,64, 65,78,84]                              | Moderate confidence | <i>"Mother: I should have the right to have a bigger parental leave [100% instead of 65% of the salary], at least during the hospitalisation period. Mother stays there [NICU] for a lot of hours alone in a very difficult situation. At least during the hospitalisation in NICU, the father and the mother should have the right to stay both with a [full parental] leave (.)." (Portugal, hospital) [32]</i><br><i>"They gave me only seven days as a holiday and I am worried they may terminate my contract should I stay here longer than expected."</i> (Malawi, hospital)[64]                                    |
| Positive relationships with staff | <b>Compassion and sensitivity:</b> Carers desire to develop a caring and sensitive relationship with HCPs caring for their baby.   | 20 studies[32,43,45,47,49, 52,55–60,64,68,70,72, 77–79,81]       | High confidence     | <i>"One of the nurses even wrote me an e-mail in the middle of the night to tell me that my baby was sleeping well. That touched me so because that was my first night at home. I found that amazing. What a calling, such a job."</i> (Switzerland, hospital)[49]<br><i>"You know they are dedicated professional individuals that care deeply about what they are doing and very compassionate....(that) allows you to focus on yourself, your daughter, and your wife."</i> (Singapore, hospital) [55]  |
|                                   | <b>Consistency in care/communication:</b> Carers want consistent rules, advice, therapeutic plans and predictions of outcome, from, and between, different HCP.  | 14 studies[35,40,42,43,45, 46,49,50,52,56,62,70,72, 81]          | Moderate confidence | <i>"To me it's just about consistency and every nurse does things differently. One nurse will tell you to do one thing and the next nurse will come in and criticise you 'cos they wind or feed a baby differently and it makes you feel like crap."</i> (UK, hospital)[42]  |

(continued on next page)



Table 4 (continued)

| Analytical theme | Descriptive theme (review finding)  | Studies contributing to review finding                         | CERQual grading     | Supporting data   |
|------------------|---|--|---------------------|---|
|                  |   |  |                     | <i>“in contact with five different public health nurses and heard five different sets of advice that were really contradictory; I had a really hard time trusting what I was being told.” (Canada, community)[70]</i>   |
|                  | <b>HCP expertise/care:</b> Carers want well-trained, competent, staff able to provide the specialist care needed by the infant.   | 9 studies[42,52,57,70,73,76–78,82]                             | High confidence     | <i>“Absolute confidence in the staff. I didn’t feel like I needed to know every step of the way. I was able to just step back, realise that control was not mine. The control was where it should be, with professionals, and they would take good care of them [the babies].” (UK, hospital)[73]</i><br><i>“I was attended to by trainees, so I did not know who was doing the right thing and (and who was doing) the wrong (thing). They (baby) were not handled in the right way.” Unsworth 2021 (Kenya, community)[76]</i><br><i>“My expectation from the nurses was that they would take good care of him, and I was relieved when I saw how they took care of him.” (Turkey, hospital)[82]</i> |
|                  | <b>Respect, collaboration and trust:</b> Carers desire the development of collaborative relationships with the HCP; where the parent is identified as an important part of the care-team with unique skills and knowledge of the baby, and is heard and understood. | 17 studies[32,42,43,45,53,56,58,61,68,72,74,75,78,79,82,84,85] | Moderate confidence | <i>“She [healthcare professional] just did not understand us, and she did not listen, and she was actually just working against us. So, we requested to have her near us as little as possible.” (Netherlands, hospital)[58]</i><br><i>“Doctor [name removed] was very good and talked to my husband. until his questions finished and he had resolutions or some kind of answers. the fact that he had been heard was really, really important. You know, you can’t always give an answer or solve the problem but at least he’d been heard.” (UK, hospital)[78]</i>   |

## 4. Discussion and Conclusion

### 4.1. Discussion

This systematic QES of a contemporary evidence-base identified eight analytic themes and 31 descriptive themes, mostly graded with high or moderate confidence. The neonatal and post-natal period is difficult for families of low birthweight and preterm infants. Whilst the ultimate desire is a good outcome for their child, we found many other issues of importance to families related to processes within healthcare. Unwelcoming hospital environments, poor logistical support, poor emotional support, non-collaborative relationships with staff, and lack of information all resulted in a limited ability for parents to engage in activities that matter most to them: to be actively involved in delivering care to, and parenting, their infant.

We identified more than 200 studies across a range of healthcare and social settings. Our sampling strategy allowed us to select 54 of these studies that represented a good geographical coverage, whilst retaining the studies with the richest data and best methodological quality. Carers’ views were surprisingly consistent across most of the evidence reviewed. However, much of the work was performed when the infant was still receiving neonatal care, or about to be transferred to a community setting. Few studies explored what mattered to carers after the initial discharge period; although findings appeared consistent even when parents had the opportunity to reflect on their neonatal journey. Where we had less certainty about what was important to families (including their ability to be involved in decisions about their infant’s care and the need for privacy), this reflected variation in how parents discussed these aspects of care, and the limited number of primary studies that presented data on these issues from both low-income and/or community settings.

Although we conducted searches in databases in which studies from low resource countries might be listed (LILACS, African Journals Online), we elected to focus on papers published in English as this was the language of the study team. It is important to acknowledge that papers published in other languages may have described parental views differently, and this is a limitation of our review.

Previous research in this field has highlighted the state of liminality that families of infants in NICU find themselves in, where carers feel like life is on hold, feel alienated, and struggle with their identity, sometimes not feeling like a real parent [87,88]. This can often lead parents to engaging in a deferential attitude towards the healthcare professional ‘experts’ as they do not wish to destabilise the status quo for fear of damaging relationships. The results of this QES enhance this picture, revealing that parents want support to be able to care for their infants and require positive relationships with staff and to feel fully informed about their infant’s progress. We also show the complex interplay of factors at work in these families’ lives, with practical, logistical, and emotional factors all being equally important to parents as they navigate through various healthcare settings with their infants.

Data from the included studies indicated that the attitudes and behaviours of HCPs have a significant influence on families. Carers want good communication and social skills and clinical competence as well as consistency between HCPs. This conclusion is consistent with previous research in neonatal units showing the importance of parent-provider communication in maintaining parental wellbeing [89], and work which suggests that a structured communication framework could promote relationship-building, information exchange, shared decision-making, and more parent involvement in healthcare [90].

### 4.2. Conclusion

It is vital that all organisations working to ensure high-quality and equitable care for small and sick newborns worldwide understand what matters to families. Although parents and family members reported a variety of care experiences, we found high consistency in what matters to families. Most studies to date have been based in, or around, neonatal units. Further research is needed on what matters to parents who require community-based care at birth or after discharge and on the views and needs of fathers and extended family members, especially in low-income settings.

### 4.3. Practice implications

Enabling a positive post-natal period for families of preterm and LBW infants is challenging. The focus of HCPs and the healthcare system is naturally on the medical needs and well-being of the infant and the parents' practical and emotional needs are secondary to this. However, this review identifies several approaches that could be implemented to improve the experience of carers. Many of these are consistent with the Family-Centred Care model of healthcare which acknowledges the role of family members in supporting the well-being of the hospitalised infant, recognising the mutually beneficial partnerships among HCPs, parents and families [13].

In this work, we attempted to include data from different countries and healthcare settings. Given this, it is perhaps surprising how coherent the wishes of carers were across studies. However, practical barriers to implementation of care affect families in different ways, and support needs to be bespoke between, and even within, different communities. Local services are therefore likely to be best placed to identify what support (for example, financial or logistic) might be most needed to improve support for families during this vulnerable period. One example of this may be the involvement of fathers in neonatal care, which is influenced by different cultural, social and legal barriers across different communities. Our conclusions in relation to fathers are graded with moderate confidence and further research is needed in low and middle-income countries to understand how best to involve and support fathers in these settings. We also found limited evidence on the views of extended family members. However, we hope that these data provide a framework for making decisions that allows for consideration of the views and needs of the wider family, especially because they are important sources of support for parents.

Preterm and LBW infants require high-quality inpatient care in dedicated facilities staffed by specialized HCPs. This provision is known to be inadequate in many settings [91]. In the absence of appropriate infrastructure and expertise, it is not surprising that families are not able to participate in shared decision-making or express expectations about consistency of care, communication, and their need for privacy. Our data therefore supports calls to “*strengthen and invest*” in care for these infants, and “*harness the power of parents, families and communities*” in these settings [12].

### Author contributions

LH, DO and FW conceived and designed the study. MM designed the search strategy (in consultation with other review authors) and performed the database searches. LH, DO, HB, ED, TI and AA screened, selected and reviewed eligible reports. LH, DO, HB, ED and FW extracted data. LH, DO and FW completed the first draft of the paper. All authors commented on and revised the paper, and approved the final version.

### Funding

This work was funded by the World Health Organization (WHO Reference 2021/1113382). WHO commissioned the review for the Guideline Development Group meeting for development of WHO recommendations on care of the preterm or LBW infant. They assisted in formulating the research question and provided inputs on the synthesis of the results and manuscript.

### CRedit authorship contribution statement

**Hurt Lisa:** Writing – review & editing, Writing – original draft, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Odd David:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Mann Mala:** Writing – review & editing, Methodology, Data curation. **Beetham Hannah:** Writing – review & editing, Methodology,

Formal analysis, Data curation. **Dorgeat Emma:** Writing – review & editing, Methodology, Formal analysis, Data curation, Conceptualization. **Isaac Thomas CW:** Writing – review & editing, Methodology, Data curation. **Ashman Annie:** Writing – review & editing, Methodology, Data curation. **Wood Fiona:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization.

### Declaration of Competing Interest

The authors declare that they have no conflicts of interest.

### Acknowledgements

We are grateful to Clive Gregory, Research Manager, for his support during the set-up of this project, and to Delyth Morris, Cardiff University Subject Librarian, and other Cardiff University library staff for their support in accessing the publications included in this review.

### Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2023.107893](https://doi.org/10.1016/j.pec.2023.107893).

### References

- [1] Murray CJL, Vos T, Lozano R, Naghavi M, Flaxman AD, Michaud C, et al. Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990–2010: a systematic analysis for the global burden of disease study 2010. *Lancet* 2012;380:2197–223.
- [2] Marlow N, Bennett C, Draper E, Hennessy M, Morgan A, Costeloe K. Perinatal outcomes for extremely preterm babies in relation to place of birth in England: the EPICure 2 study. *Arch Dis Child Fetal Neonatal Ed* 2014;99:181–8.
- [3] Lawn J, Blencowe H, Oza S, You D, Lee A, Waiswa P, et al. Every Newborn: progress, priorities, and potential beyond survival. *Lancet* 2014;384:189–205.
- [4] Santhakumaran S, Statnikov Y, Gray D, Battersby C, Ashby D, Modi N. Survival of very preterm infants admitted to neonatal care in England 2008–2014: time trends and regional variation. *Arch Dis Child Fetal Neonatal Ed* 2018;103:F208–15.
- [5] Younge N, Goldstein R, Bann C, Hintz S, Patel R, Smith P, et al. CM. C. Survival and neurodevelopmental outcomes among periviable infants. *N Engl J Med* 2017;376:617–28.
- [6] Lagerstrom M, Bremme K, Erenoth P, Janson C. Long-term development for girls and boys at age 16–18 as related to birth weight and gestational age. *Int J Psychophysiol* 1994;17:175–80.
- [7] Johnson S, Hennessy E, Smith R, Trikic R, Wolke D, Marlow N. Academic attainment and special educational needs in extremely preterm children at 11 years of age: the EPICure study. *Arch Dis Child Fetal Neonatal Ed* 2009;94:F283–9.
- [8] World Health Organization. WHO recommendations on interventions to improve preterm birth outcomes, [https://www.who.int/reproductivehealth/publications/maternal\\_perinatal\\_health/preterm-birth-guideline/en/](https://www.who.int/reproductivehealth/publications/maternal_perinatal_health/preterm-birth-guideline/en/); 2015 [accessed May 28 2021].
- [9] Blencowe H, Cousens S, Oestergaard M, Chou D, Moller A, Narwal R, et al. National, regional, and worldwide estimates of preterm birth rates in the year 2010 with time trends since 1990 for selected countries: a systematic analysis and implications. *Lancet* 2012;379:2162–72.
- [10] Blencowe H, Krusevec J, De Onis M, Black R, An X, Stevens G, et al. National, regional, and worldwide estimates of low birthweight in 2015, with trends from 2000: a systematic analysis. *Lancet Glob Health* 2019;7:e849–e60.
- [11] World Health Organization. WHO recommendations for care of the preterm or low-birth-weight infant, [https://www.who.int/publications/i/item/9789240058262\\_2022](https://www.who.int/publications/i/item/9789240058262_2022) [accessed 30 January 2023].
- [12] World Health Organization & UNICEF. Survive and Thrive. Transforming care for every small and sick newborn, [https://www.who.int/publications/i/item/9789241515887\\_2019](https://www.who.int/publications/i/item/9789241515887_2019) [accessed March 14 2022].
- [13] Gooding J, Cooper L, Blaine A, Franck L, Howse J, Berns S. Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. *Semin Perinatol* 2011;35:20–8.
- [14] Henderson J, Carson C, Redshaw M. Impact of preterm birth on maternal well-being and women's perceptions of their baby: a population-based survey. *BMJ Open* 2016;6:e012676.
- [15] Lakshmanan A, Agni M, Lieu T, Flegler E, Kipke M, Friedlich P, et al. The impact of preterm birth <37 weeks on parents and families: a cross-sectional study in the 2 years after discharge from the neonatal intensive care unit. *Health Qual Life Outcomes* 2017;15:38.
- [16] Webbe J, Duffy J, Alfonso E, Al-Muzaffar I, Brunton G, Greenough A, et al. Core outcomes in neonatology: development of a core outcome set for neonatal research. *Arch Dis Child Fetal Neonatal Ed* 2020;105:425–31.

- [17] Janvier A, Farlow B, Baardsnes J, Pearce R, Barrington K. Measuring and communicating meaningful outcomes in neonatology: a family perspective. *Semin Perinatol* 2016;40:571–7.
- [18] Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Method* 2012;12:1–8.
- [19] World Health Organization. Preterm birth, <https://www.who.int/news-room/factsheets/detail/preterm-birth>; 2018 [accessed May 28 2021].
- [20] World Health Organization & UNICEF. Low birthweight estimates. Levels and trends 2000–2015, <https://apps.who.int/iris/bitstream/handle/10665/324783/WHO-NMH-NHD-19-21-eng.pdf?ua=1>; 2019 [accessed May 28 2021].
- [21] Critical Appraisal Skills Programme. CASP Qualitative Checklist, [https://casp-uk.b-cdn.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018\\_fillable\\_form.pdf](https://casp-uk.b-cdn.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf); 2018 [accessed May 28 2021].
- [22] Effective Practice and Organisation of Care (EPOC). EPOC Qualitative Evidence Syntheses guidance on when to sample and how to develop a purposive sampling frame. EPOC Resources for review authors, <http://epoc.cochrane.org/resources/epoc-resources-review-authors>; 2017 [accessed June 9 2021].
- [23] Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Method* 2008;8:45.
- [24] Lumivero. NVivo (Version 12) , released 2018. [www.lumivero.com](http://www.lumivero.com).
- [25] Lewin S, Booth A, Glenton C, Munthe-Kaas H, Rashidian A, Wainwright M, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. *Implement Sci* 2018;13:2.
- [26] Munthe-Kaas H, Bohren M, Glenton C, Lewin S, Noyes J, Tunçalp Ö, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings - paper 3: how to assess methodological limitations. *Implement Sci* 2018;13:9.
- [27] Colvin C, Garside R, Wainwright M, Munthe-Kaas H, Glenton C, Bohren M, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings - paper 4: how to assess coherence. *Implement Sci* 2018;13:13.
- [28] Glenton C, Carlsen B, Lewin S, Munthe-Kaas H, Colvin C, Tunçalp Ö, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings - paper 5: how to assess adequacy of data. *Implement Sci* 2018;13:14.
- [29] Noyes J, Booth A, Lewin S, Carlsen B, Glenton C, Colvin C, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 6: how to assess relevance of the data. *Implement Sci* 2018;13:4.
- [30] Abeasi DA, Emelife B. What mothers go through when the unexpected happens: a look at challenges of mothers with preterm babies during hospitalization in a tertiary institution in Nigeria. *J Nurs Midwifery Sci* 2020;7:22–9.
- [31] Adama EA, Sundin D, Bayes S. Ghanaian fathers' experiences of caring for preterm infants; a journey of exclusion. *J Neonatal Nurs* 2017;23:275–81.
- [32] Amorim M, Alves E, Kelly-Irving M, Silva S. Needs of parents of very preterm infants in neonatal intensive care units: a mixed methods study. *Intensive Crit Care Nurs* 2019;54:88–95.
- [33] Arnold L, Sawyer A, Rabe H, Abbott J, Gyte G, Duley L, et al. Very preterm birth qualitative collaborative G. parents' first moments with their very preterm babies: a qualitative study. *BMJ Open* 2013;3:e002487.
- [34] Aydon L, Hauck Y, Murdoch J, Siu D, Sharp M. Transition from hospital to home: Parents' perception of their preparation and readiness for discharge with their preterm infant. *J Clin Nurs* 2018;27:269–77.
- [35] Blomqvist YT, Rubertsson C, Kylberg E, Joreskog K, Nyqvist KH. Kangaroo Mother Care helps fathers of preterm infants gain confidence in the paternal role. *J Adv Nurs* 2012;68:1988–96.
- [36] Brodsgaard A, Zimmermann R, Petersen M. A preterm lifeline: Early discharge programme based on family-centred care. *J Spec Pedia Nurs* 2015;20:232–43.
- [37] Chang Lee S, Long A, Boore J. Taiwanese women's experiences of becoming a mother to a very-low-birth-weight preterm infant: a grounded theory study. *Int J Nurs Stud* 2009;46:326–36.
- [38] Dorner RA, Boss RD, Burton VJ, Raja K, Lemmon ME. Parent preferences for neurodevelopmental screening in the neonatal intensive care unit. *Dev Med Child Neurol* 2020;62:500–5.
- [39] dos Santos LC, Balamintu T, Deggau Hegeto de Souza SN, Giovanini, Rossetto E. Perception of premature infants' mothers on home visits before and after hospital discharge. *Invest Educ Enferm* 2014;32:393–400.
- [40] Feeley N, Waitzer E, Sherrard K, Boisvert L, Zolkowitz P. Fathers' perceptions of the barriers and facilitators to their involvement with their newborn hospitalised in the neonatal intensive care unit. *J Clin Nurs* 2013;22:521–30.
- [41] Fernandez-Medina IM, Granero-Molina J, Hernandez-Padilla JM, Jimenez-Lasserotte MDM, Ruiz-Fernandez MD, Fernandez-Sola C. Socio-family support for parents of technology-dependent extremely preterm infants after hospital discharge. *J Child Health Care* 2022;26:42–55.
- [42] Finlayson K, Dixon A, Smith C, Dykes F, Flacking R. Mothers' perceptions of family centred care in neonatal intensive care units. *Sex Reprod Health* 2014;5:119–24.
- [43] Franck LS, McNulty A, Alderdice F. The perinatal-neonatal care journey for parents of preterm infants. What is working and what can be improved. *J Perinat Neonat Nurs* 2017;31:244–55.
- [44] Gallegos-Martinez J, Reyes-Hernandez J, Scochi CG. The hospitalized preterm newborn: the significance of parents' participation in the neonatal unit. *Rev Lat Am Enferm* 2013;21:1360–6.
- [45] Glazer KB, Sofaer S, Balbierz A, Wang E, Howell EA. Perinatal care experiences among racially and ethnically diverse mothers whose infants required a NICU stay. *J Perinatol* 2021;41:413–21.
- [46] Granrud MD, Ludvigsen E, Andershed B. Parents' experiences of their premature infants' transportation from a university hospital NICU to the NICU at two local hospitals. *J Pedia Nurs* 2014;29:e11–8.
- [47] Guillaume S, Michelin N, Amrani E, Benier B, Durrmeyer X, Lescure S, et al. Parents' expectations of staff in the early bonding process with their premature babies in the intensive care setting: a qualitative multicenter study with 60 parents. *BMC Pedia* 2013;13:18.
- [48] Hägi-Pedersen M-B, Kronborg H, Norlyk A. Knowledge of mothers and fathers' experiences of the early in-home care of premature infants supported by video consultations with a neonatal nurse. *BMC Nurs* 2021;20:1–10.
- [49] Hendriks MJ, Abraham A. End-of-life decision making for parents of extremely preterm infants. *J Obstet Gynecol Neonatal Nurs* 2017;46:727–36.
- [50] Ignell Mode R, Mard E, Nyqvist KH, Blomqvist YT. Fathers' perception of information received during their infants' stay at a neonatal intensive care unit. *Sex Reprod Health* 2014;5:131–6.
- [51] Jantsch LB, Alves TF, Arrue AM, Toso B, Neves ET. Health care network (dis) articulation in late and moderate prematurity. *Rev Bras Enferm* 2021;74:e20200524.
- [52] Kim AR. Addressing the needs of mothers with infants in the neonatal intensive care unit: a qualitative secondary analysis. *Asian Nurs Res* 2020;14:327–37.
- [53] Klawetter S, Neu M, Roybal KL, Greenfield JC, Scott J, Hwang S. Mothering in the NICU: A qualitative exploration of maternal engagement. *Soc Work Health Care* 2019;58:746–63.
- [54] Leonard A, Mayers P. Parents' lived experience of providing kangaroo care to their preterm infants. *Health SA* 2008;13:16–28.
- [55] Lian BX, Amin Z, Sensaki S, Aishworiya R. An active pursuit of reassurance-coping strategies of fathers with infants in the Neonatal Intensive Care Unit. *J Perinatol* 2020;10:10.
- [56] Liu LX, Mozafarinia M, Axelin A, Feeley N. Parents' experiences of support in NICU single-family rooms. *Neonatal Netw* 2019;38:88–97.
- [57] Lomotey AY, Bam V, Dijji AK, Asante E, Asante HB, Osei J. Experiences of mothers with preterm babies at a Mother and Baby Unit of a tertiary hospital: a descriptive phenomenological study. *Nurs Open* 2020;7:150–9.
- [58] Lorie ES, Wreesmann WW, van Veenendaal NR, van Kempen A, Labrie NHM. Parents' needs and perceived gaps in communication with healthcare professionals in the neonatal (intensive) care unit: A qualitative interview study. *Patient Educ Couns* 2021;104:1518–25.
- [59] Lundqvist P, Weis J, Sivberg B. Parents' journey caring for a preterm infant until discharge from hospital-based neonatal home care-a challenging process to cope with. *J Clin Nurs* 2019;28:2966–78.
- [60] Mihae I, Jina O. Nursing support perceived by mothers of preterm infants in a neonatal intensive care unit in South Korea. *Child Health Nurs Res* 2021;27:146–59.
- [61] Ncube RK, Barlow H, Mayers PM. A life uncertain - My baby's vulnerability: mothers' lived experience of connection with their preterm infants in a Botswana neonatal intensive care unit. *Curatationis* 2016;39:e1–9.
- [62] Neu M, Klawetter S, Greenfield JC, Roybal K, Scott JL, Hwang SS. Mothers' experiences in the NICU before family-centered care and in NICUs where it is the standard of care. *Adv Neonatal Care* 2020;20:68–79.
- [63] Noren J, Nyqvist KH, Rubertsson C, Blomqvist YT. Becoming a mother - mothers' experience of Kangaroo mother care. *Sex Reprod Health* 2018;16:181–5.
- [64] Nyondo-Mipando AL, Kinshella MW, Salimu S, Chiwaya B, Chikoti F, Chirambo L, et al. "It brought hope and peace in my heart": Caregivers' perceptions on kangaroo mother care services in Malawi. *BMC Pedia* 2020;20:541.
- [65] Olsson E, Eriksson M, Anderzen-Carlsson A. Skin-to-skin contact facilitates more equal parenthood - a qualitative study from fathers' perspective. *J Pedia Nurs* 2017;34:e2–9.
- [66] Orapriyakul R, Jirapaet V, Rodcumdee B. Struggling to get connected: the process of maternal attachment to the preterm infant in the neonatal intensive care unit. *Thai J Nurs Res* 2007;11:251–63.
- [67] Petty J, Jarvis J, Thomas R. Understanding parents' emotional experiences for neonatal education: a narrative, interpretive approach. *J Clin Nurs* 2019;28:1911–24.
- [68] Petty J, Jarvis J, Thomas R. Listening to the parent voice to inform person-centred neonatal care. *J Neonatal Nurs* 2019;25:121–6.
- [69] Petty J, Whiting L, Green J, Fowler C. Parents' views on preparation to care for extremely premature infants at home. *Nurs Child Young People* 2018;05:05.
- [70] Premji SS, Currie G, Reilly S, Dosani A, Oliver LM, Lodha AK, et al. A qualitative study: Mothers of late preterm infants relate their experiences of community-based care. *PLoS One* 2017;12:e0174419.
- [71] Rossman B, Engstrom JL, Meier PP, Vonderheid SC, Norr KF, Hill PD. "They've walked in my shoes": Mothers of very low birth weight infants and their experiences with breastfeeding peer counselors in the Neonatal Intensive Care Unit. *J Hum Lact* 2011;27:14–24.
- [72] Russell G, Sawyer A, Rabe H, Abbott J, Gyte G, Duley L, et al. Very Preterm Birth Qualitative Collaborative G. Parents' views on care of their very premature babies in neonatal intensive care units: a qualitative study. *BMC Pedia* 2014;14:230.
- [73] Sawyer A, Rabe H, Abbott J, Gyte G, Duley L, Ayers S. Very Preterm Birth Qualitative Collaborative G. Parents' experiences and satisfaction with care during the birth of their very preterm baby: a qualitative study. *BJOG* 2013;120:637–43.
- [74] Skene C, Franck L, Curtis P, Gerrish K. Parental involvement in neonatal comfort care. *J Obstet Gynecol Neonatal Nurs* 2012;41:786–97.
- [75] Treherne SC, Feeley N, Charbonneau L, Axelin A. Parents' perspectives of closeness and separation with their preterm infants in the NICU. *J Obstet Gynecol Neonatal Nurs* 2017;46:737–47.
- [76] Unsworth S, Barsosio HC, Achieng F, Juma D, Tindi L, Omitti F, et al. Caregiver experiences and health care worker perspectives of accessing health care for low birth weight infants in rural Kenya. *Paediatr Int Child Health* 2021;41:145–53.

- [77] Veronez M, Borghesan NAB, Correa DAM, Higarashi IH. Experience of mothers of premature babies from birth to discharge: notes of field journals. *Rev Gauch Enferm* 2017;38:e60911.
- [78] Villeneuve E, Landa P, Allen M, Spencer A, Prosser S, Gibson A, et al. A framework to address key issues of neonatal service configuration in England: the NeoNet multimethods study. PMID. Southampton, UK: NIHR Journals Library; 2018.
- [79] Wernet M, de Carvalho Mesquita Ayres JR, Silveira Viera C, Moraes Leite A, Falleiros de Mello D. Mother recognition in the neonatal intensive care unit. *Rev Bras Enferm* 2015;68:203–9.
- [80] Yu XY, Zhang J, Yuan L. Chinese parents' lived experiences of having preterm infants in NICU: a qualitative study. *J Pediatr Nurs* 2020;50:E48–54.
- [81] Adcock A, Cram F, Edmonds L, Lawton B, He Tamariki Kokoti Tau: families of Indigenous infants talk about their experiences of preterm birth and Neonatal Intensive Care. *Int J Environ Res Public Health* 2021;18:18.
- [82] Gundogdu N.A., Mert Z.T., Gunduz E.S. Not being able to hug our baby before the cables: Early experiences of parents with premature babies. *Nurs Forum*.
- [83] Hua W, Wang L, Li C, Simoni JM, Weichao Y, Jiang L. Understanding preparation for preterm infant discharge from parents' and healthcare providers' perspectives: challenges and opportunities. *J Adv Nurs* 2021;77:1379–90.
- [84] Merritt L, Maxwell J, Urbanosky C. The needs of NICU fathers in their own words: a qualitative descriptive study. *Adv Neonatal Care* 2022;22:E94–101.
- [85] Namusoke F, Sekikubo M, Namiro F, Nakigudde J. "What are you carrying?" Experiences of mothers with preterm babies in low-resource setting neonatal intensive care unit: a qualitative study. *BMJ Open* 2021;11:e043989.
- [86] Nyondo-Mipando AL, Kinshella M-LW, Hiwa T, Salimu S, Banda M, Vidler M, et al. Mothers' quality of life delivering kangaroo mother care at Malawian hospitals: a qualitative study. *Health Qual Life Outcomes* 2021;19:1–8.
- [87] Flacking R, Ewald U, Starrin B. "I wanted to do a good job": experiences of 'becoming a mother' and breastfeeding in mothers of very preterm infants after discharge from a neonatal unit. *Soc Sci Med* 2007;64:2405–16.
- [88] Jackson K, Ternstedt B, Schollin J. From alienation to familiarity: experiences of mothers and fathers of preterm infants. *J Adv Nurs* 2003;43:120–9.
- [89] Labrie NH, van Veenendaal NR, Ludolph RA, Ket JC, van der Schoor SR. Effects of parent-provider communication during infant hospitalization in the NICU on parents: a systematic review with meta-synthesis and narrative synthesis. *Patient Educ Couns* 2021;104:1526–52.
- [90] Wreesman WW, Lorie ES, van Veenendaal NR, van Kempen AA, Ket JC, NH L. The functions of adequate communication in the neonatal care unit: a systematic review and meta-synthesis of qualitative research. *Patient Educ Couns* 2021;104:1505–17.
- [91] Moxon S, Lawn J, Dickson K, Simen-Kapeu A, Gupta G, Deorari A, et al. Inpatient care of small and sick newborns: a multi-country analysis of health system bottlenecks and potential solutions. *BMC Pregnancy Childbirth* 2015;15:S7.