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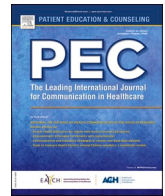
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# What matters to families about the healthcare of preterm or low birth weight infants: A qualitative evidence synthesis

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## 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,

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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”

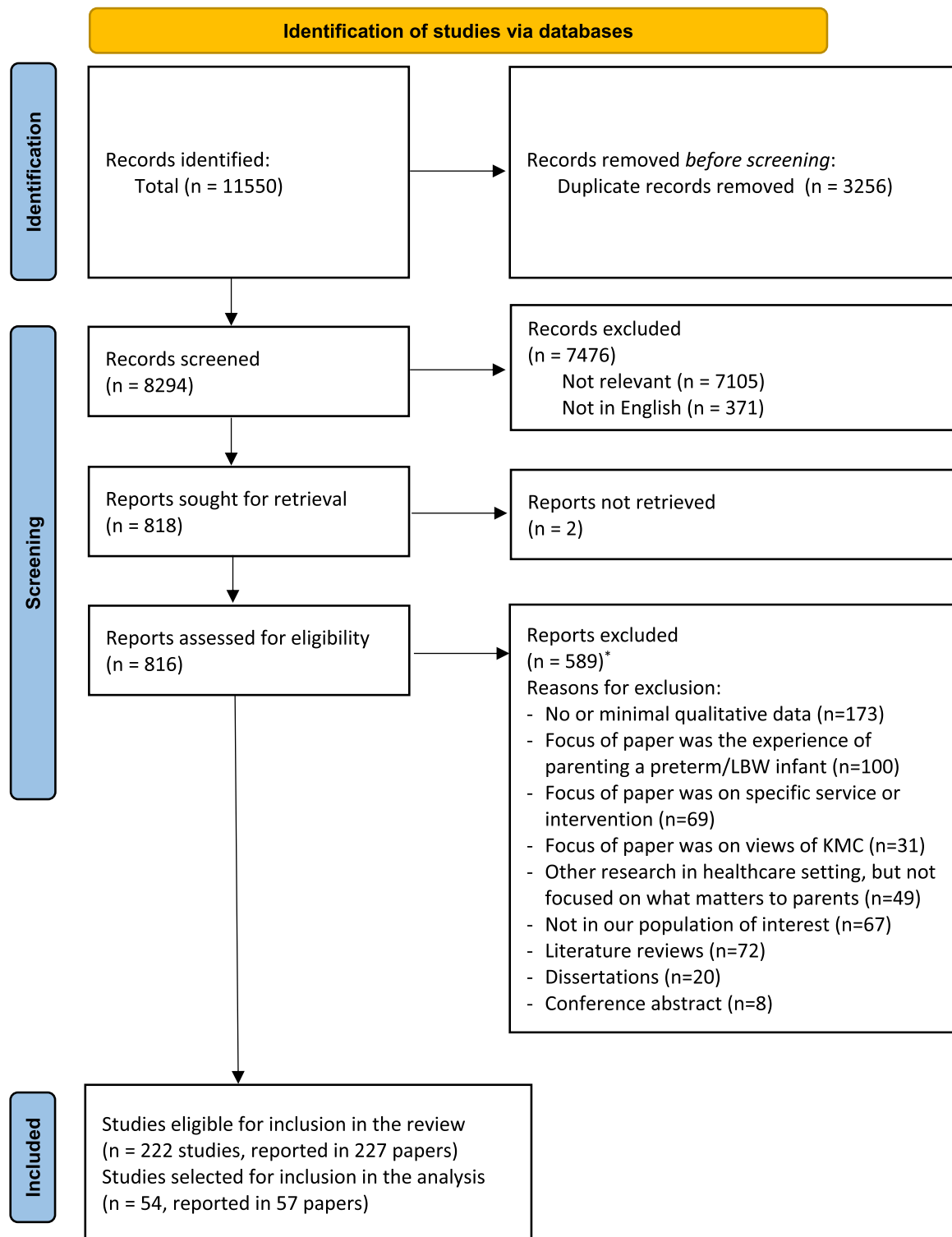


Fig. 1. PRISMA flow diagram.

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) 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) 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 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)) Thematic content analysis	Neonatal unit	Recruited from all seven public level III NICU in the Northern Health Region 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) Thematic analysis	Neonatal unit	Recruited from three NICU in tertiary care hospitals in South East England 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 Thematic analysis	Neonatal unit & transition post-discharge	Recruited at a tertiary maternity hospital 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) Thematic content analysis	Neonatal unit	Recruited from NICUs in two hospitals 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) 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) 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) 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

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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) 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) Thematic content analysis	Neonatal unit	Participants from two NICUs in a major Canadian urban centre 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) 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) 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") 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) 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) 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) 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) 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 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

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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) 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) 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 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) 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) 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) 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) 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) 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) 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) Thematic content analysis	Neonatal unit	Convenience sampling from a level III NICU; identified by NICU nurses who assisted with recruitment	4	Good

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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) 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) 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) 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 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) 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 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) 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) 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) 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) 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]) 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) Constant comparative analysis	Neonatal unit	Three participants purposively sampled in two NICUs (one public university, one provincial hospital),	3	Good

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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
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 (high)	Sept-Nov 2017	Qualitative interviews (conducted at the family home) Constant comparative analysis	Discharge from NICU & community	then subsequent theoretical sampling Purposive sampling via the coordinator of an NHS trust-based parent support group	4	Good
Petty 2019b (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 (high)	Not reported	Qualitative interviews (conducted at the family home or a private location) Thematic analysis	Neonatal unit, discharge from NICU & community	Purposive sampling; volunteers were requested through a key gatekeeper linked to a UK parent support charity who disseminated the recruitment call nationally using their established email contact database.	4	Good
Premji 2017	To explore mothers' experiences of caring for their late preterm infants in the community	Canada (high)	April 2013- June 2014	Qualitative interviews (conducted at the family home or a private location) Interpretative thematic analysis	Community	Multistage purposeful sampling to achieve rich narratives and diversity from four hospitals in Calgary; \$50 grocery gift card incentive	3	Good
Rossmann 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 (high)	Oct 2008- Mar 2009	Qualitative interviews (conducted in hospital whilst infant was admitted) Thematic content analysis	Neonatal unit	Convenience sampling, approached by NICU practitioner at a tertiary care NICU	3	Good
Russell 2014 & Sawyer 2013 (2 papers)	To explore parents' views and experiences of the care for their very premature infant on NICU (Russell 2014) 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 (high)	June – Nov 2011	Qualitative interviews (conducted in hospital or in the family home) Inductive thematic analysis	Neonatal unit	Recruited from three tertiary care centres in England using posters in NICU or posted/ personally-given letters; parents returned a card if they wanted to 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 (high)	Jan – Nov 2008	Focussed ethnography, with participant observations and qualitative interviews (in NICU) Inductive thematic analysis	Neonatal unit	Approached by researcher in a regional NICU	5	Good
Treherne 2017	To discover parents' perceptions of closeness to and separation from their preterm infants in the NICU	Canada (high)	Feb 2015 – Jan 2016	Qualitative data collected through diary voice app (for 24 h) Thematic content analysis	Neonatal unit	Purposive sampling in an urban level III NICU, with parents approached by NICU staff	4	Good
Unsworth 2021	To explore caregiver experiences and healthcare provider perspectives of accessing healthcare for low birth weight infants in rural Kenya	Kenya (lower- middle)	June 2019	Qualitative interviews (conducted within the research area of the hospital) Thematic analysis	Community	Convenience sampling from neonatal and postnatal ward registers at a county hospital or those known to community health volunteers; contacted by telephone or home 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 (upper- middle)	Oct-Dec 2011	Daily journal written by mothers Thematic content analysis	Neonatal unit	Recruited from neonatal units by researcher who was a member of nursing staff	3	Good
Villeneuve 2018	To identify outcomes that were important to families of	UK (high)	2016–2017	Qualitative interviews (conducted at a	Neonatal unit	Participants purposively sampled	5	Good

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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) 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) 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) 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 <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 <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

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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 <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 <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 <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 <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 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

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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 <b>Excluded:</b> Participants who gave birth to two or more infants; or if infants were stillborn	20 (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. <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 <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 (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 <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 <b>Excluded:</b> Infants with grade 4 intraventricular haemorrhage, trisomy 21 or other chromosomal abnormalities, in	15 (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

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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 <b>Included:</b> Mothers with babies born < 37 weeks <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 <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 <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 <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

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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) <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

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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 <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 <b>Excluded:</b> History of mental illness; infants were abandoned or deceased	15 (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>

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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	<i>"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."</i> (Denmark, community)[48] <i>"I would like to see better parent support from GPs, from consultants, from health visitors, a better understanding."</i> (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	<i>"We learned everything we needed and knew what we had to do, I was quite comfortable when we went home."</i> (Denmark, hospital and community)[36] <i>"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."</i> (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	<i>"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."</i> (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>"I have my in-laws...they are always there, whether it be for moral or practical support."</i> (Canada, hospital)[40] <i>"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."</i> (Grandmother, Malawi, hospital)[64] <i>"Only direct siblings are allowed to see the babies. To me that's the white way of thinking, we're Māori."</i> (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	<i>"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."</i> (Botswana, hospital)[61] <i>"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."</i> (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>"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."</i> (father, South Africa, hospital)[54] <i>"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?"</i> (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	<i>"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."</i> (USA, hospital)[71] <i>"... 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."</i> (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	<i>"You cannot just touch your baby when you want to, you have to be given the go ahead from the staff."</i> (Nigeria, hospital)[30] <i>"I saw him just a moment, how small he was. After</i>

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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] "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] "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] "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] "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] "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] "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] "I mean, I knew it was busy but they still do not have the

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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] <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] <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] <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] <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>"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]</i>
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] <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> <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> <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> <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.

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### 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.

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### 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).

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