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Understanding the co-construction of safety in the paediatric intensive care unit: A meta-ethnography of parents' experiences

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Abstract

Background: Children experiencing critical illness or injury may require admission to a paediatric intensive care unit (PICU) to receive life-sustaining or life-saving treatment. Studies have explored the experience of parents with a child in PICU but tend to focus on subgroups of children or specific healthcare systems. Therefore, we aimed to undertake a meta-ethnography to draw together the published research.

Methods: A systematic search strategy was developed to identify qualitative studies, which had explored the experiences of parents with a critically ill child treated in a PICU. A meta-ethnography was undertaken following the structured steps of identifying the topic; undertaking a systematic search; reading the research; determining how the studies relate and translate into each other; and synthesising and expressing the results.

Results: We identified 2989 articles from our search and after a systematic series of exclusions, 15 papers remaining for inclusion. We explored the original parent voices (first order) and the interpretation of the study authors (second order) to identify three third-order concepts (our interpretation of the findings), which related to technical, relational and temporal factors. These factors influenced parents' experiences, providing both barriers and facilitators to how parents and caregivers experienced the time their child was in the PICU. The dynamic and co-constructed nature of safety provided an analytical overarching frame of reference.

Conclusion: This synthesis demonstrates novel ways in which parents and caregivers can contribute to the vital role of ensuring a co-created safe healthcare environment for their child when receiving life-saving care within the PICU.

KEYWORDS
paediatric intensive care, parent experience, safety

1 | BACKGROUND

Admission to PICU represents the need for advanced medical support and intervention to survive critical illness or injury. However, this can be a particularly traumatic time for children and their families. Around half of all PICU admissions are of very young children aged less than 2 years (PICANet, n.d.) who are therefore unable to advocate for themselves. Length of stay in PICU can be quite short with reported median stays being approximately 2 days (Pollack et al., 2018). However, in recent years, the population requiring critical care has changed, with increasing numbers of children have long-term health conditions necessitating longer PICU stays (Kanthimathinathan et al., 2020).

Many parents and families understandably feel overwhelmed when their child is admitted to PICU, particularly by the technical equipment, alarms and medical language (Board & Ryan-Wenger, 2003; Haines & Childs, 2005). The admission can feel 'like being in another world' (Dahav & Sjöström-Strand, 2018), and it can have a lasting impact, both negatively and positively, on the family (Colville et al., 2009). Research has suggested that the altered parental role is a particular stressor (Board & Ryan-Wenger, 2002; Harbaugh et al., 2004) and that active participation in their child's care can be a key coping strategy (Hill, 1996). The parent's role within PICU is varied, with previous research identifying their importance as multifaceted but including that of a caregiver; entertainer (Snowdon & Gottlieb, 1989); and participator in their child's child and having a role to share their parental expertise (Ames et al., 2011). Outside of PICU, research has shown a parent's role to include responsibility and safety within a healthcare environment including checking the accuracy of medication (Cox et al., 2017; Harden, 2005).

Historically, PICUs had restrictive visiting for parents and many did not allow siblings or extended family to visit (Frazier et al., 2010; Giannini & Miccinesi, 2011). Various reasons were used to justify this including minimising infection; minimising trauma for all involved; and lack of physical space (Meert et al., 2013). In more recent years, the importance of family-centred care has been promoted, and increasingly, in many countries, open access for parents had become more commonplace (Meert et al., 2013) although this has been heavily restricted in some places during the COVID-19 pandemic (Bichard & Herring, 2020). As we emerge from the effects of the pandemic, the fragmenting of family centred care requires us to reflect on pre-pandemic context and the role/experiences of parental presence during their child's critical illness.

1.1 | Aim

Whilst individual studies have explored the experience of parents with a child in PICU, these have often focussed on subgroups of children or have been restricted to individual countries and thus healthcare services. Therefore, the aim of our work was to synthesise the published empirical evidence and thus generate new analytical insights

> **Key messages**
> - To our knowledge, this is the first meta-ethnography exploring the experiences of parents within the PICU environment.
> - We have identified the important role of parents in ensuring a co-created safe healthcare environment for their child to receive life-saving care.
> - Healthcare professionals need to be aware of the active contributions parents make to safety within the PICU and undertake practices that enhance and enable this to occur.

and understanding of the parental experience, inclusive of the roles they took on, whilst having a child in the PICU.

2 | METHODS

We chose to conduct a meta-ethnography, as it is one of the most well-developed methods for synthesising qualitative data and sits within the interpretative paradigm, which aligns with most methods of qualitative research (Britten et al., 2002). Meta-ethnography is a systematic approach to a review, taking data from multiple studies to generate new insights into the experiences and perspectives of, in our case, parents of critically ill children. Our approach was based on the seven steps proposed by Noblit and Hare (1988). Our review ascribed to a constructivist epistemology where knowledge is seen as being generated in the social world, through the interaction between the researcher and the researched (Bailey, 1997), and subsequently aids the researcher in analysis and interpretation. A realist ontology was adopted that gains access to an underlying reality through the synthesis of varied and multiple perspectives, which is not apparent on the examination of individual accounts or papers (Walsh & Devane, 2012).

We included qualitative research written in English and published from 2000 onwards to restrict to contemporary PICU care. We excluded studies for duplicates; conference abstracts; studies based solely in neonatal care or outside a PICU setting; research from a low-income country (high income as defined by the Organisation for Economic Co-operation and Development; https://www.oecd.org/); experiences of healthcare professionals; research about a specific experience (e.g. parents witnessing their child's resuscitation); and studies about the end of life.

2.1 | Step 1: Getting started

We defined our research question: *What are the experiences of parents with a critically ill child in the PICU?* We did not restrict our research by

excluding studies that focussed on children with specific health conditions (e.g. meningitis).

2.2 | Step 2: Deciding what is relevant to the initial interest

We undertook our literature review using defined criteria and search strategy. We searched CINAHL, PsycINFO, Medline and Scopus using pre-defined search criteria (see Appendix A).

We focussed on peer-reviewed qualitative papers that published and presented data from 2000 onwards. If studies presented quotes from parents and healthcare professionals, we only considered the parent quotes. If it was unclear if the paper should be included, we contacted the original study authors for additional information.

2.3 | Step 3: Reading the studies

Initially, papers were read and re-read to identify any key themes. Summary information was produced about each study, and the studies were assessed for quality using the prompts suggested by Dixon-Woods et al. (2004). There are conflicting suggestions of how to deal with quality in qualitative research. Rather than take a checklist approach to quality appraisal, which tends to prioritise the technical aspects of the research, we assessed papers based on their contribution to the topic under question. We accepted that different authors had differing aims and approaches with their research, all of which contributed something original to the research field (Morse, 2021) and therefore excluded no papers based on perceived quality. Study quality was initially assessed by one author (SES) and presented and discussed with other authors (JM and NM) to confirm agreement.

2.4 | Steps 4 and 5: Determining how the studies are related and translating the studies into one another

Next, the lead author (SS) undertook line-by-line coding of the original parent voices in the presented quotes alongside the themes of each independent study. These codes were taken to a subgroup of the authors (SS, JM, NM) to iteratively identify and discuss themes that were common or different across studies.

2.5 | Step 6: Synthesising the results

First- and second-order constructs were synthesised to develop the third-order constructs. We translated the findings of one paper into another by comparing the findings from each study through collective discussion of new themes that we identified when looking at data across all the studies. The synthesis step was an iterative process, initially exploring the broader parental experience before focussing on the role parent's play in the creation of a safe environment for their child. The subgroup met regularly over a period of several months until confident of the explanatory value of our interpretations.

2.6 | Step 7: Expressing the synthesis

We collaboratively produced the results that are presented in this paper. We followed recommendations from the eMERGe reporting guidance (France et al., 2019) to ensure we described each stage of our meta-ethnography comprehensively.

3 | RESULTS

3.1 | Identification and selection of studies

We identified 2989 papers that met our search criteria (Figure 1). After initial exclusions, a total of 116 papers were read in full to determine their eligibility, and following additional exclusions, 13 papers remained. We reviewed the reference lists of those papers and identified an additional two papers for inclusion. In total, 15 papers were included in our meta-ethnography (Alzawad et al., 2020; Colville et al., 2009; Dahav & Sjöström-Strand, 2018; Dampier et al., 2002; Diaz-Caneja et al., 2005; Engström et al., 2015; Geoghegan et al., 2016; Graham et al., 2009; Hagstrom, 2017; Haines, 2005; Henderson et al., 2017; Latour et al., 2011; Oxley, 2015; Rennick et al., 2019; Simeone et al., 2018). We assessed quality using prompts rather than a checklist (Dixon-Woods et al., 2004). This cued our attention to the phenomena being studied and the value of the product rather than the technical detail. All included studies had clear research questions, were suited to a qualitative approach and were assessed as contributing to the field. Some issues of quality were identified, for example, providing no information about the included parents, and these are highlighted in Appendix B.

3.2 | Characteristics of included studies

Information about the included studies can be found in Table 1. The identified papers represented the views of over 250 parents, over 100 of whom were fathers. The original researchers interviewed parents with a broad range of experiences; some papers focussed on the whole PICU population (Alzawad et al., 2020; Colville et al., 2009; Dampier et al., 2002; Diaz-Caneja et al., 2005; Engström et al., 2015; Latour et al., 2011; Oxley, 2015), whilst others focussed on children with specific characteristics such as a long PICU stay (Geoghegan et al., 2016; Hagstrom, 2017), cardiac problems (Dahav & Sjöström-Strand, 2018; Simeone et al., 2018), meningitis (Haines, 2005) or chronic critical illness (Graham et al., 2009; Henderson et al., 2017; Rennick et al., 2019). Six studies excluded the parents of children who died (Colville et al., 2009; Dahav & Sjöström-Strand, 2018; Dampier et al., 2002; Engström et al., 2015; Haines, 2005; Latour et al., 2011),
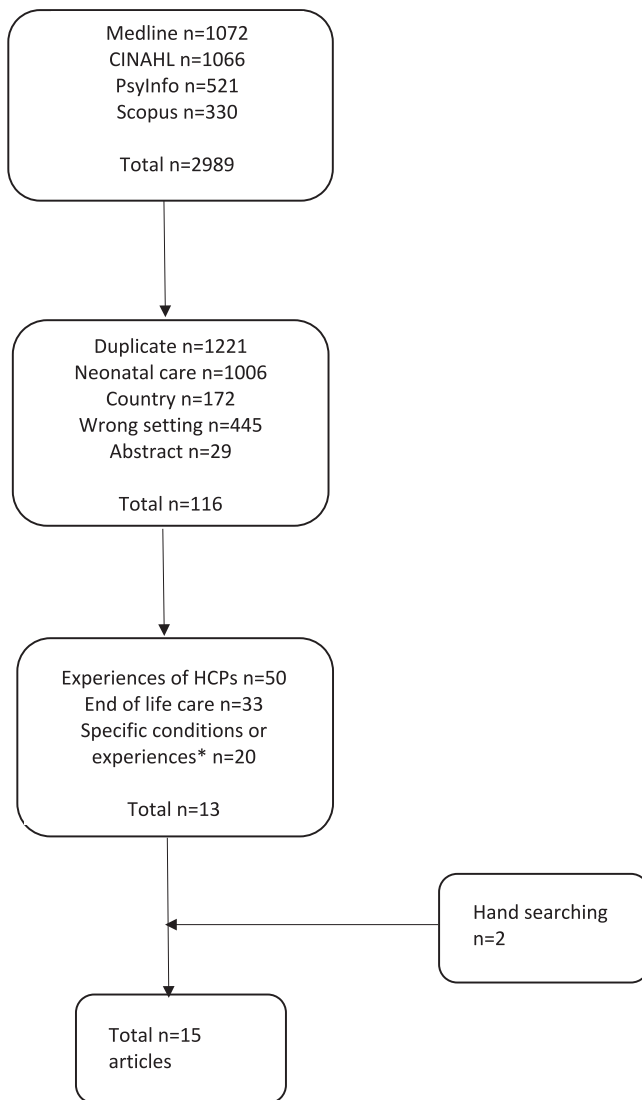
FIGURE 1 Flowchart of the included and excluded studies. *For example, how parents coped with seeing their child be resuscitated, transition from ICU.

and a further three excluded children who were receiving end of life care (Alzawad et al., 2020; Diaz-Caneja et al., 2005; Hagstrom, 2017). Studies were based in the United Kingdom (Colville et al., 2009; Dampier et al., 2002; Diaz-Caneja et al., 2005; Geoghegan et al., 2016; Haines, 2005; Oxley, 2015); the United States (Alzawad et al., 2020; Graham et al., 2009; Hagstrom, 2017; Henderson et al., 2017); Sweden (Dahav & Sjöström-Strand, 2018; Engström et al., 2015); the Netherlands (Latour et al., 2011); Canada (Rennick et al., 2019); and Italy (Simeone et al., 2018).

3.3 | Synthesis

We extracted the quotes of parents (first order) and undertook line by line coding whilst also considering the original themes. We

found similarities across papers and formed a total of 14 second-order constructs (Table 2). These second-order constructs were grouped together into three third-order constructs, which represented factors that impacted on families throughout their experience of being in PICU. For example, the following second-order constructs were grouped to form the third-order construct 'relational': always being responsible; not being a parent; bringing care continuity; being the expert; informing safety; and planning/decision making (Table 2). We have provided a worked example of how the higher order constructed were generated in Table 3. The three third-order constructs related to technical, relational and temporal factors that influenced how parents experienced having a critically ill child in PICU. A visual representation of these factors is found in Figure 2. These third-order constructs represented both barriers and facilitators to how parents experienced the time their child was in the PICU.

3.4 | Third-order construct: Technical factors

Medical technology and equipment provided a visual and constant reminder for parents of the sickness of their child. Whilst parents recognised the equipment was necessary to keep their child safe and alive, it shaped the interpretation and realisation of how ill their child was. It was for some a barrier, physically and emotionally separating them from their child (Simeone et al., 2018) and impacting on their identity as a parent (Geoghegan et al., 2016). However, for other parents, being able to participate in the provision of technology-enabled care offered a means to learn and be involved in day-to-day routines (Geoghegan et al., 2016).

The alarms from medical equipment caused high levels of anxiety and reinforced the seriousness of the situation (Table 2, Q1, Q2), and for some, this was an image they had trouble forgetting (Q3). Other parents talked about how alarms disrupted sleep (Alzawad et al., 2020) and made it difficult to concentrate on their child (Colville et al., 2009).

Whilst technology changed the way they saw their child (Q4), it also offered an opportunity for parents to communicate with medical teams by allowing interactions with shared knowledge, for example, parents being able to keep track of monitors and learning what normal ranges were (Q5, Q6). Similarly, some parents wanted to learn more and proactively asked to join ward rounds (Q8) to ensure they learned what to do to 'make sure I wouldn't do more harm when I got home' (Graham et al., 2009). Technology therefore provided a route for parents to learn and become experts in their child's clinical care. However, staff remained the guardians of this technological knowledge and the gatekeepers for parents to be able to learn and be involved, with some staff inclined to only allow parents to get involved if they were assessed as capable (Q7). At the extreme, some parents reported that 'there are some nurses who would let us do stuff and then some who wouldn't' (Geoghegan et al., 2016).

TABLE 1 Summary of the characteristics of the children and parents from the included studies.

Study (country and year)	Aim	Study design and methods	Information about the children	Study methodology	Information about the parents
Alzawad et al (Pacific Northwest, USA, interviews in 2018, published in 2020)	• To describe the experiences of parents whilst their child was in PICU	• Semi-structured face-to-face interviews at the child's bedside or in a PICU quiet room • Analysed using methods adapted from grounded theory	• Children admitted for >48 h with exclusions if they were receiving end-of-life care • Aged 1 month to 17 years • Median PICU stay: 4 days (range: 2–171 days)	• Not clear	• 15 parents (2 fathers and 13 mothers). Note: Parents included biological parents, grandparents, foster parents and guardians • Parents were aged 20–60 years (median 34 years) and English speaking • ~87% white and ~47% were college graduates
Colville et al (London, UK, published in 2008)	• To establish rates of psychological distress in parents and help explain that distress in parents who have had a child in PICU	• Interviews 8 months after PICU admission • Parents were interviewed separately at home in the evenings/weekends • Mixed methods: Asked four open-ended questions (three related to PICU and one related to coping since) and then completed standardised questionnaires • Analysed using a thematic analysis	• Admitted for >24 h with exclusions if the child died or was readmitted • Aged 0–15.1 years • Median PICU stay: 4 days (range: 1–16 days)	• Not clear	• 32 mothers and 18 fathers (17 mother–father pairs who were interviewed separately) • Mother median age: 37 years and fathers: 38.5 years
Dahav et al (South Sweden, interviews in 2015, published in 2018)	• To describe parent's experience of having a child admitted to PICU	• Interviews 1–4 weeks after PICU stay • Three interviews were at home, seven at the PICU and two on the phone (parent preference) • An open interview where parents were asked to share their experience and then researcher provided prompts • Analysed using a qualitative content analysis	• Admitted ≥3 days, with exclusions if the child died • Eleven children had congenital cardiac problems, and one had a diaphragmatic hernia • Median PICU stay: 7 days (range: 4–16 days)	• Not clear	• Parents of 12 children (i.e. 15 parents: Seven mothers, two father, three couples) • Swedish speaking
Dampier et al (English PICU published in 2002. Contacted study author to find out data collection was in 2001)	• To explore the pathways and experiences of families when their child is critically ill	• Interviewed at home 1–2 months after discharge • The focus was on the sequential journey from realising the child was ill to home again	• A convenience sample of children admitted to PICU during the study period • Children who died were excluded	• Phenomenological	• 15 families
Diaz-Caneja et al (St Marys. Published in 2005 but no year given for data collection)	• To compare the experiences of parents and children during inpatient admission to either a paediatric intensive care unit (PICU) or a general paediatric ward (GPW) with a specific focus on identifying factors which may influence psychological outcome	• Parents were interviews 6–12 months after admission. Purposive sample stratified by child's gender, school age and diagnosis • Comparative analysis	• Respiratory problems main reason for admission • Mean age: 9.6 years • Children were excluded with terminal illness, neurological disorder, admission from overdose and meningitis	• Not clear	• 11 parents of PICU children (9 PGW as comparison group—not included in this work) • One father and 10 mothers • ~60% White and English speaking

(Continues)

TABLE 1 (Continued)

Study (country and year)	Aim	Study design and methods	Study methodology	Information about the children	Information about the parents
Engstrom et al (one of three ICU in Sweden in 2012. The ICUs were adult ICUs who cared for some children)	• To describe the experience of parents who have a critically ill child in ICU	• Semi-structured interviews • Content analysis	• Not clear	• Children aged between 1 and 17 years • One child was mechanically ventilated • Children who died were excluded	• Seven parents (two fathers and five mothers) of six children
Geoghegan et al (a paediatric hospital which included a PICU, CICU and NICU in the United Kingdom)	• To understand the experience of parents of children in PICU/ICU/PCICU to improve the mechanisms that provide support	• Study includes both staff and families • Semi-structured interviews which took place in quiet rooms or at home • Analysed using a framework analysis	• Not clear	• Children were aged from newborn to 2 years • Children had a long stay (>28 days in PICU/NICU or >14 days in CICU)	• 18 families (seven mothers, three fathers and four parent pairs) • Healthcare professionals recruited to the original work but excluded from this work
Graham et al (PICU in Boston, USA, in 2006)	• To describe the experience of PICU hospitalisation from the perspective of parents of children with severe antecedent disabilities	• Semi-structured interview held in a private location. Two interviewers • Thematic analysis	• Not clear	• Children with antecedent disabilities who had all had prior admission to PICU • Children were aged 1–20 year	• Eight parents (one father, seven mothers) • Six were White. Non-English-speaking parents were excluded
Hagstrom (tertiary centre in the United States. Interviewed in 2015 and published in 2016)	• To hear the experiences of people who routinely care for children with chronic illnesses in ICU	• Mixed methods starting with open-ended question then questionnaire then more open-ended questions • Analysis was van Manen approach for uncovering thematic aspects of a phenomenon	• Not clear	• Children who had been on the unit 5 days to 2 weeks and likely to require 4–8 weeks more • Ages ranged from 9 days to 18 years • Exclusions included length of stay more than 2 weeks on another unit during this admission; acute event in last 48 h; suspected child abuse; DNR; EoL	• Nine parents (eight mothers and one father) of eight children • All married and White • Parents were excluded if foster carers or <18 years
Haines (unclear but published in 2005 and author based at Bristol PICU)	• The aims of the study were (1) to describe, analyse and try to understand the lived experience of parents whose child has suffered from and survived severe meningitis; (2) to generate concepts and theories regarding the parents' experiences; (3) to identify factors that could positively influence and develop the quality of care provided by nurses and the multidisciplinary team	• Interviews took place 1 month after discharge from PICU at home or in the hospital	• Phenomenological	• Children who survived severe meningococcal disease • Five children aged 13 months to 15 years • PICU length of stay was 4 days to 3 weeks	• Seven parents (four mothers, one father and one mother–father pair)

TABLE 1 (Continued)

Study (country and year)	Aim	Study design and methods	Study methodology	Information about the children	Information about the parents
Henderson et al (recruited from 2015 to 2016 from five metropolitan areas of the United States)	• To hear the experiences of people who routinely care for children with chronic illnesses in ICU	• Semi-structured interviews over the phone or in person • Content analysis was conducted	• Not clear	• Children with chronic critical illness, defined as those requiring repeated, prolonged ICU admissions	• Seven English-speaking parents but no additional information • Parents were recruited via websites and patient groups but unclear when their experience needed to have been • Healthcare professionals recruited to the original work but excluded from this work.
Latour et al (seven PICUs in the Netherlands. Interviews conducted from 2006 to 2007, published in 2010)	• Explore and identify parent's experiences of a PICU admission of their child	• Interviewed within 1 month of discharge from PICU • Analysed using a thematic analysis	• Not clear	• 41 children admitted to PICU in the Netherlands (approximately equal numbers from each PICU) • Age median: 16 months (IQR: 4–75 months) • Median PICU LOS: 8 days (IQR: 4–13) • Children who died in or after PICU excluded	• Sixteen mothers, two fathers and 23 mother–father pairs • Mother mean age: 35 (range: 19–49), fathers mean age: 37 (28–49)
Oxley et al (Southampton, UK, PICU. Interviews conducted in 2011, published in 2015)	• To explore the lived experiences of parents whose children have been admitted to PICU	• Five unstructured interviews up-to 1 year after discharge. Took place in the parent's home and one on the children's ward • Analysis was an interpretative phenomenological analysis	• Phenomenological	• Emergency, first admission of a child to PICU who was not cared for by the study team	• Five mothers and one couple (father not present for entire interview so researchers considered them as one participant)
Rennick et al (Canadian PICU. Data collected in 2015–2016)	• To explore the experiences of parents of children with medical complexity during PICU admission.	• Interview data were analysed using the constant comparative method. All investigators read the transcriptions and undertook line-by-line coding. Codes and categories were validated with participants. The team agreed when saturation had been reached	• Not clear	• All children admitted who met the definition of complex had their parents approached in a 12-month period • 14 children with median PICU length of stay of 10 days (range: 1–76 days). • Median age was 4.5 years (range: 10 months to 18 years)	• Seven mothers, four fathers and three mother–father pairs • ~90% were married
Simeone et al (Italian paediatric cardiac intensive care unit [PCICU], data collection year unclear but published in 2018)	• To describe the lived experience of mothers and fathers whilst their child is in PCICU (paediatric cardiac intensive care unit)	• Nested component of a larger study. Interviewed by two people in their own homes. Analysis was undertaken by two researchers who analysed independently. Followed the approach of Cohen	• Phenomenological	• Nine children with first diagnosis of a congenital heart disease • Average age was 3 years, and average length of stay was 5.2 days	• 16 parents (nine mothers and seven fathers) • Italian speaking

TABLE 2 Reciprocal synthesis: key components of parents' experience of having a child in the PICU, with illustrative quotes.

Third-order constructs	Second-order constructs Key components	First-order constructs Illustrative quotes
Technical factors	(1) Role of machines/equipment; (2) physical appearance of a sick child altered by machinery; (3) staff interactions depends on parent's technical ability; (4) having technical questions to get answered; and (5) using the PICU to learn through involvement in care	Q1: 'the seriousness of the situation with all the appliances, all the beeping' (Engström et al., 2015) Q2: 'when the alarms were going off … for the first three days … my heart just went berserk' (Colville et al., 2009) Q3: 'I never took my eyes off the monitor, I watched that more than I watched her' (Haines, 2005) Q4: 'If I hadn't seen him on the ventilator, I would have probably thought he was all right, but because I've seen that, it's stuck in my head' (Dampier et al., 2002) Q5: 'I realised about sats and blood gases and why they're doing this, it was much easier because then I knew what they were doing …' (Geoghegan et al., 2016) Q6: 'I wanted to keep track, watch the monitors, I felt safe when I was able to find out that it remained stable' (Engström et al., 2015) Q7: 'when the nurse sees that you are logical in what you do, and you do the right things at the right times, she is more inclined to let you go' (Rennick et al., 2019) Q8: 'I remember asking if I can join rounds because I had so many questions' (Graham et al., 2009)
Relational factors	(6) Always being responsible; (7) not being a parent; (8) bring care continuity; and (9) planning/decision making	Q9: 'when she was in intensive care, I did not seem to be a mom; well, I couldn't protect her, help her …' (Simeone et al., 2018) Q10: 'the child is left with a parent who actually doesn't know what to do' (Geoghegan et al., 2016) Q11: 'they're the medical professionals, and we're the professionals of our child' (Rennick et al., 2019) Q12: 'I try to bring in pictures of her, something to show that this is what she is really like. Because they do not know' (Graham et al., 2009) Q13: 'we told [staff], "don't suction past a certain point. She will gag. She will throw up". That advice was not heeded. She threw up all her feedings because she was suctioned deep … so listen to the people who take care of her on a regular basis …' (Henderson et al., 2017) Q14: 'sometimes I felt more on top of it than anyone else … I'd sit there day in day out … there were times someone said, 'we might need to do this' and, I was "you did that yesterday"' (Geoghegan et al., 2016) Q15: 'they're looking at it like we're taking their job away or they're annoyed by us being there … we're his parents, we're adding an extra hand' (Rennick et al., 2019) Q16: '… it is a hospital and it is not the safest place to be …. In addition to being a mom, you are a bodyguard and everything else' (Graham et al., 2009) Q17: 'I try to help and sometimes I do and sometimes I am told very kindly just to step aside, which I do, I do not argue with that but we are expected to be experts at home …' (Graham et al., 2009) Q18: 'if I have a nurse that I do not know, I will not leave' (Graham et al., 2009)
Temporal factors	(10) Taking it a day at a time; (11) living with uncertainty; (12) living in the PICU; (13) separation from child and family; and (14) managing the transfer out of PICU	Q19: 'I'm so torn … I didn't want to hurt my other child, but I want to help this child, I wish I could clone myself' (Hagstrom, 2017) Q20: 'when you walk back up is your door gonna be open, and is there gonna be 50 doctors in here? And all you did was go change a load of laundry …' (Alzawad et al., 2020) Q21: 'this time I wasn't allowed to follow inside that room (x-ray), and it felt really hard, even if there might be an

TABLE 2 (Continued)

Third-order constructs	Second-order constructs Key components	First-order constructs Illustrative quotes
		explanation .... I cried and felt very alone while I was waiting' (Engström et al., 2015)
		Q22: 'I didn't want to hear about what's going to happen tomorrow, it was enough learning about today' (Dahav & Sjöström-Strand, 2018)
		Q23: 'at first it was like ... you're waiting every second for something to change or not change, and ... you kind of get used to just waiting' (Hagstrom, 2017)
		Q24: 'I did not want to say to (doctor): Could he die? I did not want to ask because I did not want to hear it' (Diaz-Caneja et al., 2005)
		Q25: 'the horrible thing was that my little girl was getting better and ready to leave and his was getting worse ... she was going to die' (Colville et al., 2009)
		Q26: 'okay it's a change of shift, who are we going to get ...' (Geoghegan et al., 2016)
		Q27: 'being on the wards is like being out on the streets' (Oxley, 2015)
		Q28: 'the pediatric ward has no knowledge of trachea cannula care. We can do it but we are not 24 h on the ward ...' (Latour et al., 2011)

3.5 | Third-order construct: Relational factors

Being in the PICU impacted on the relationships parents had with their child. For some parents, being in PICU represented a loss of the parenting role and identity (Q9, Q10). For others, especially if their child was young or a newborn, this was their only experience of being a family in the first place: 'we were leaving this routine [in PICU] that had become our normal ... that was life and it was more than the life we'd known ...' (Geoghegan et al., 2016). Despite feeling unable to be a parent to their sick child, some parents still felt responsible for their child even in PICU (Q11). They advocated for their child, ensuring healthcare professionals knew what they were like before they were ill (Q12). Some parents had knowledge of their child's clinical care outside of PICU and wanted to be partners in their child's care. They offered advice and expertise, although this was not always heeded or appreciated (Q13, Q15, Q17).

Some parents wanted to have a role within the PICU and as the natural protector of their child, and the person most constantly at the bedside, were able to spot issues that healthcare professionals missed (Q14). Some parents felt responsible for their child's admission and wanted to be at the bedside constantly: '... I couldn't leave her in the ICU as it was my entire fault' (Engström et al., 2015). The relationships with staff were essential to help facilitate some parents taking time away from the PICU. Some felt that leaving the PICU meant 'you were putting your own needs before your child' (Geoghegan et al., 2016). One parent reported how when they left the PICU they could hear their child screaming alone (Dampier et al., 2002), and for others, if they were unsure about the staff, they would stay with their child (Q18).

3.6 | Third-order construct: Temporal factors

The time in PICU was particularly difficult for some families when there were siblings at home who also needed support (Q19). Leaving their child in the PICU alone for any amount of time could be difficult for parents. For some, even a brief trip-out resulted in anxiety about what might happen whilst they were gone (Q20). Being asked to leave, even for short periods of time, for clinical procedures, distressed some parents (Q21).

The passage of time played out differently throughout the PICU experience, some parents wanted to take it day-by-day (Q22), but others knew that life in PICU involved lots of patience and waiting (Q23). Living with prolonged uncertainty was difficult, and some families were afraid that their child could die (Q24). Even when their child improved, for some parents, there was a constant reminder of what could have happened because there were other children around them critically ill, and sometimes dying (Q25).

Changes in the PICU could be difficult for some parents, not knowing which staff were coming on the next shift (Q26). Finally, when the time in the PICU came to an end, some parents felt like they were unsupported to manage the transition to the ward (Q27, Q28).

4 | DISCUSSION

This meta-synthesis of 15 primary research papers has provided novel insights into the phenomena of having a critically ill child on the PICU from the perspective of parents and caregivers. Across the studies, a

TABLE 3 A worked example from two of the included papers to demonstrate the process to synthesise the third order constructs.

	Author's theme	Second-order constructs	Third-order constructs
Graham et al	Know my child's baseline	Bring care continuity	Relational
	Heterogeneity within group	Bring care continuity Planning/decision making	
	Disconnect between role of parent at home versus parent in PICU	Always being responsible Bring care continuity	
	PICU care does not equate with respite	Always being responsible	
Rennick et al	We know our child best	Bring care continuity Always being responsible Planning/decision making	
	When expertise collides	Bring care continuity Always being responsible Planning/decision making	
	Negotiating care boundaries	Always being responsible Planning/decision making	
	The importance of being known	Bring care continuity	
Graham et al	PICU care does not equate with respite	Taking it a day at a time	Temporal
	High stakes learning environment	Managing the transition out of PICU	
	Lack of fit within the acute care model	Managing the transition out of PICU	
Rennick et al	Know my child's baseline	Managing the transition out of PICU	
	When expertise collides	Living in the PICU Managing the transition out of PICU	
	Negotiating care boundaries	Living in the PICU	
Graham et al	Disconnect between role of parent at home versus parent in PICU	Staff interactions depends on parent's technical ability	Technical
	High-stakes learning environment	Having technical questions to get answered Using the PICU to learn through involvement in care	
Rennick et al	When expertise collides	Having technical questions to get answered	
	Negotiating care boundaries	Staff interactions depends on parent's technical ability	
	The importance of being known	Staff interactions depends on parent's technical ability	
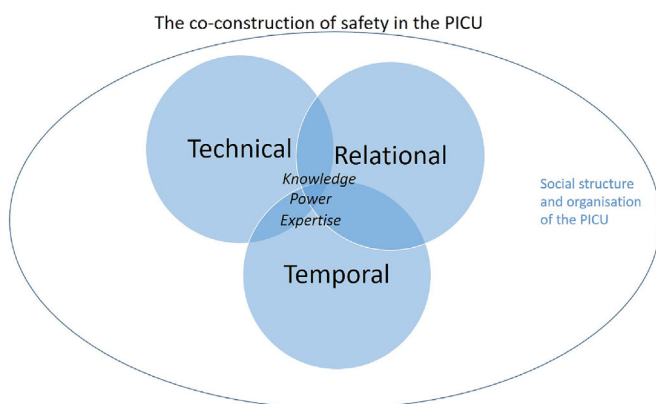
FIGURE 2 A visual representation of the co-construction of safety in PICU.

multiplicity of divergent and unique experiences of parents were identified. However, from our analysis, we highlighted parental experiences are situated and related to technical, temporal and relational factors. The dynamic and co-constructed nature of safety underpins and links these factors, specifically in relation to the importance of parents' involvement in the care of their child.

Expertise and epistemic authority are mediated by interpersonal relationships and play a vital role within the PICU, both between staff-parents and parents-children. Parents possess unique tacit knowledge of their child; they provide the continuity of care before, during and after the PICU stay. They offer a form of 'scaffolding' and 'knowledge brokering' to supplement the care provided by healthcare professionals (O'Hara et al., 2019). This level of 'patient safety work' (Mackintosh et al., 2017) tends to remain implicit, which may deny the opportunity for staff to work productively with parents to share responsibilities

around 'co-producing' the quality and safety of their children's care (Hor et al., 2013). In our work, we identified that the parental experience contributed to the safety of their child, and it was personal and realised in the interactions between children, families and healthcare professionals in a similar way to work from primary care (Rhodes et al., 2016). This builds on the evidence base that parental experiential knowledge is significant for clinicians, especially in paediatrics, where family members are often the first to recognise that something is wrong and seek help for their child (Ray et al., 2009).

Whilst the practices that generate safety in the PICU can involve parents, we also see the significance of professional hierarchies, boundaries and asymmetries of power for *how* safety is co-constructed. However, the centrality of relationships acts as a mediating influence, helping to bridge divides. Our synthesis extends previous evidence demonstrating how responsive communication and negotiable patient–provider interactions are important for patient safety (Carroll, 2014; Hor et al., 2013; Rhodes et al., 2016).

Temporality holds significance for parents experiencing PICU, given that time is filled with flux and change amidst clinical and prognostic uncertainty (Mackintosh & Armstrong, 2020). This evidence synthesis builds on previous studies that highlight the work parents undertake to navigate and cope with the multiple uncertainties associated with children's clinical conditions and the technical and practical competence they develop to care for their children at home (including interpretive skills around when to seek help) (Hinton & Armstrong, 2020).

Parents interact with technologies to create order and structure in critical care. These interactions can be understood as safety-generating practices, and they supplement the coherent, coordinated responses of staff to managing the clinical situation at hand (Mesman, 2008). This view is in some ways contrary to the conventional and previously portrayed view of parents as emotionally wounded and largely static bystanders (Abela et al., 2020), but our findings identify the importance of parents as active and dynamic partners in the creation of a safe environment to care for their child. However, whilst some parents were empowered by technology, others found it reinforced the seriousness of their child's condition and heightened anxiety, exacerbating the trauma they were already experiencing (Colville et al., 2009; Engström et al., 2015).

Our evidence synthesis shows that parental information needs vary, considering both short-term possibilities and longer-term potentials of their children's conditions. Interpretative resources need to be available to help parents make sense of their children's illness and information needs to be personalised. Without this, there is a risk of hermeneutic injustice as parents struggle to articulate and give meaning to their experiences (Fricker, 2007). They should also provide information to the healthcare team, being empowered to provide an active voice in decision making. Patients in other settings compensate for inefficiencies in healthcare services (e.g. repeating medical histories when notes are missing) (Vincent & Davis, 2012) but in PICU, this vital, informal role generally falls to parents and family as the young age and sickness of admitted children means they are rarely able to advocate for themselves. There have been calls, which this work supports, to involve both patients and their families and view their contribution as a source of insight, rather than disrupting and adding variability to the system (O'Hara et al., 2019).

4.1 | Strengths and limitations

Whilst it is possible we did not identify all research to be included in this work, a strength of our approach was that the search strategy was conducted in a systematic and rigorous manner. All stages of the analysis were discussed by a subgroup of the authors (SES, JM and NM) in an iterative manner. The authors have different disciplinary backgrounds (epidemiology, nursing, medical and sociology), and reflections about positionality formed part of the interpretive process. We held regular team meetings to review the data and discuss interpretations and analysis. However, there were limitations to our approach. We restricted our analysis to papers written in English due to language abilities of the study team, and therefore, important work from non-English-speaking countries may have been overlooked. We only had access to the data provided by the original study authors in their published papers, and we relied on their interpretations of the findings. Finally, our results have to be interpreted within the context of the data we used, for example, the exclusion of non-English-speaking parents by some studies.

5 | CONCLUSION

To our knowledge, this is the first meta-ethnography exploring the experiences of parents within the PICU environment. We have identified the important role of parents in ensuring a co-created safe healthcare environment for their child to receive life-saving care. Professionals working within this clinical area need to be cognisant of the complex, active and inter-relational role parents have to safety and undertake practices that enhance and enable this to occur. Future clinical work should focus on promoting and encouraging parents to be active participants, not just in their child's day-to-day care but also the creation of a PICU-wide safe environment.

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APPENDIX A: SEARCH STRATEGY

Search term capturing information about	
Child	pediatric OR paediatric OR child* OR infant
Parent	parent* OR guardian* OR mother OR father
Setting of care	intensive care unit OR intensive care OR critical care unit OR critical care OR ICU OR PICU OR PCCU
Experience	feeling* OR support OR emotion* OR experience
Study design	qualitative OR qual* OR interview OR focus groups

Note: The search terms for child, parent, setting of care, experience and study design were combined using the AND Boolean operator.

APPENDIX B: OVERVIEW OF ASSESSMENT OF STUDY QUALITY

Study	Are the research questions clear?	Is qualitative inquiry appropriate?	Are the sampling, data collection and analysis described?	Are the sampling, data collection and analysis appropriate?	Are the claims supported by evidence?	Are the data and interpretations clearly integrated?	Does the paper make a useful contribution?
Alzawad et al	Yes	Yes	Yes: Interview questions are provided	Unclear: There were some exclusions, but the authors acknowledged the limitations	Unclear: Some discussion of services which should be provided, but this was not explicitly talked about in interviews	Unclear: The theory of stress is mentioned in methods but not referred to again	Yes: Although interviewing parents whilst their child was in PICU meant their situation was ongoing and offered no time for reflection
Colville et al	Yes	Yes	Yes: Interview questions provided	Yes: Unclear what time frame recruitment was over (e.g. winter vs. summer) changing demographics of children	Somewhat: References made to results which were not in this paper but could be found elsewhere	Yes: Although findings compare mothers and fathers but limited discussion of this	Yes
Dahav et al	Yes	Yes	Yes	Yes: All children were newborns and nearly all treated for cardiac conditions, but this may reflect the PICU population	Yes: Cautious interpretation of (e.g.) follow-up support given the limitation of their data	Yes	Yes
Dampier et al	Somewhat: There was no specific aim expect to hear the experiences of parents	Yes	Somewhat: Unclear where and when data collection occurred (clarified with authors to ensure eligible to include in this work)	Somewhat: No information provided about the parents or children	Yes: This is mainly a descriptive paper to explore the pathways experienced by parents of critically ill children.	Yes	Yes
Diaz-Caneja et al	Yes	Yes	Yes	Yes	Somewhat: In places claims are made with no supporting quotes	Somewhat: Several of the theme/topics have no supporting quotes provided	Yes
Engstrom et al	Yes	Yes	Somewhat: Unclear how parents were selected. Interview guide is provided	Somewhat: The children were receiving care in an adult ICU which may have affected the selection of children	Yes	Yes	Yes
Geoghegan et al	Yes	Yes	Yes: Clear definition of long stay and clear approach to analysis outlined	Somewhat: There are limitations (long stay families may have good relationships with people doing the recruitment) which the authors acknowledge	Somewhat: Comparison made to non-long stay children is from the literature, and the authors acknowledge this limitation	Yes	Yes: An increasingly important group of children

Study	Are the research questions clear?	Is qualitative inquiry appropriate?	Are the sampling, data collection and analysis described?	Are the sampling, data collection and analysis appropriate?	Are the claims supported by evidence?	Are the data and interpretations clearly integrated?	Does the paper make a useful contribution?
Graham et al	Yes	Yes	Somewhat: No clear definition for 'antecedent disability', but the authors described clearly what they did	Somewhat: One of the interviewers was a clinician who had provided care to the child, and it is unclear the impact this may have had	Yes	Yes	Yes
Hagstrom	Yes	Yes	Yes: The sampling is well described	Somewhat: The topic guide is provided, and some questions appeared quite quantitative (e.g. 'to what extent …')	Yes	Yes	Yes
Haines	Yes	Yes	Yes	Yes: Only small numbers of children were eligible due to focussing on a specific clinical condition	Yes	Yes	Yes
Henderson et al	Yes	Yes	Yes: This paper recruited parents and healthcare professionals, so quotes from each are limited	Yes: Although limited by the fact they recruited via advocacy groups which the authors acknowledge	Yes	Yes	Yes
Latour et al	Yes	Yes	Yes	Yes	Yes: All the themes are supported by quotes, and subthemes are clearly described	Yes	Yes
Oxley	Yes	Yes	Yes	Yes	Yes: Each theme provides clear quotes and evidence to support the findings	Yes	Yes
Rennick et al	Yes	Yes	Yes: Example interview questions provided	Yes	Yes: All themes have substantial quotes to support them	Yes	Yes
Simeone et al	Yes	Yes	Yes	Somewhat: Participants were sampled from a larger study that there was limited information about within this study	Yes	Yes	Yes