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The lived experiences of critically ill infants hospitalised in neonatal intensive care: A scoping review

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ABSTRACT

Background: Neonatal intensive care saves lives, but the environment in which this occurs is complex and has been shown to negatively disrupt some aspects of an infant's early development. Identifying these negative effects has relied on measuring physiological and behavioural responses. Little research has sought to understand and learn from what an individual infant can communicate about their lived experience.
Aim: To examine what is known of the lived experiences of infants hospitalised in neonatal intensive care.
Study design: A scoping review using the revised Arksey and O'Malley framework was undertaken. Relevant studies, exploring an infant's experience of hospitalisation were identified through a comprehensive, systematic literature search.
Results: 4955 articles were retrieved, 88 full texts reviewed, and 23 studies included. We identified no studies that assessed the experience from the infant's perspective. The infant experience was explored using quantitative methodology, characterising, and describing the experience in measurable physiological, behavioural, and neurodevelopmental terms or through the lens of medical outcomes. The environment is described as too loud and too bright and infants are exposed to high levels of medical handling, impacting on physiology, behaviour, sleep, feeding, and both short- and longer-term outcomes.
Conclusion: The studies captured in this review focused on quantitative, measurable outcomes as a proxy for the experience as it might be felt, interpreted, and processed by an infant. Medical focus has been crucial to advance the field of neonatology, but the review highlights an important gap; the need to explore and better understand the infant's experience through their eyes.

1. Introduction

The neonatal intensive care unit (NICU) provides care for premature and critically ill infants. Progressive advancements in both perinatal and neonatal intensive care have led to dramatic improvements in the survival of premature infants and those with congenital anomalies. However, despite improved survival rates, poorer neurodevelopmental outcomes persist amongst infants hospitalised in the newborn period [1–5].

Early childhood is the most critical and vulnerable time in any child's development. It is a time when the cumulative effects of both positive and negative experiences on brain growth are remarkably profound and can strongly shape future health outcomes [6,7]. Research has demonstrated that while the skills, knowledge and actions of neonatal staff coupled with sophisticated medical technologies are capable of providing extraordinary lifesaving measures following birth, the unique NICU environment and the infant's experience of hospitalisation may be disruptive to several key aspects of early development [8].

It was previously assumed that newborns were not sensitive to their environment and hence not capable of interaction [9]. However, it is

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now evident that infants respond to their environment, utilising their sensory experiences as a platform for learning and so the intensity of sensory stimuli within the NICU environment has become a focus of interest [10]. A complex interplay of environmental factors within the NICU setting, including long periods of separation from their parents, inconsistent caregivers, the sound and light environment, touch and handling from clinical staff, and acute and chronic exposure to stressful/painful stimuli have all been shown to impact upon early life experiences, influencing both short- and longer-term outcomes [11].

Research which has examined the broader impacts of the NICU environment has led to significant changes. For example, studies detailing the deleterious effects of the constant noise and bright lights of NICU on infant's physiological and behavioural wellbeing and medical outcomes, have led to recommendations to promote and maintain a healing environment, which aims to minimise sensory overload [12–18]. Another aspect of the NICU environment that has been of particular interest is the infant's experience of pain. A landmark study in 1987 led to significant advancements in the understanding and management of neonatal pain [19]. Evidence has since demonstrated a causal link between repeated exposure to painful, stressful procedures and handling during hospitalisation and changes in brain structure and function, which impact on longer-term neurodevelopmental outcomes [3,20,21].

There is an already well-established body of literature addressing approaches to support the infant during hospitalisation, which place the infant at the centre of care processes within NICU, to ameliorate where possible, the harmful negative effects of hospitalisation on the developing infant and their family [22–24]. Despite these transformative changes, neurodevelopmental disabilities remain the most common, and potentially the most damaging, sequalae of complicated childhood disease [25]. This calls for a potentially new, exploratory area of research within NICU which aims to achieve a deeper understanding of the infant's experience of hospitalisation through the eyes and communication of the infants themselves, hoping to contribute to and enrich the neonatal literature, inform practice and bring about change to the way neonatal care is delivered.

The qualitative research paradigm of phenomenology may provide this alternative means to conduct a comprehensive and child-centred analysis of an individual infant's NICU experience. In simple terms, phenomenology seeks to understand and describe the essence of a lived phenomenon (in this case the human experience of being hospitalised in NICU) [26]. For the purposes of this scoping review, the lived experience, defined in phenomenological terms, is to gather *what* an infant experiences during hospitalisation and *how* they are experiencing life, within the NICU environment [26,27]. Using this definition and scope of interest, this review sought literature which reported or discussed the experience of the individual infant from the perspective of the infant's lived experience. We were interested in papers which analysed an infant's daily encounters, activities, and opportunities for developing connections and relationships with others. We were particularly interested in studies which focused on whether and how an infant communicates what they are experiencing and how those caring for the infant interpret the infant experience. The infant's lived experience, explored in this way, may be the missing piece in neonatal research that compliments family-centred, patient-focused care; proving that hospitalised infants are more than just a pathology, they are individuals with their own capabilities, vulnerabilities, and needs.

The purpose of this scoping review is to examine what is already known of the lived experiences of infants hospitalised in NICU. A scoping review design was chosen as it allows a range of literature to be gathered to provide an overview of what has been written on this topic, including the types of empirical studies that have been conducted and the overall focus of the literature. Our aims are to provide an overview of the infant's personal experience within NICU, identify any salient gaps, and to suggest directions for future research.

2. Method

2.1. Design

The methods for this scoping review were informed by the six-stage framework outlined by Arksey and O'Malley and revised by Levac and colleagues [28,29].

2.1.1. Stage 1: identifying the research question

Following the guideline for scoping reviews, we developed a broad research question for our literature search, asking *what is known of the lived experiences of infants hospitalised in NICU*?

2.1.2. Stage 2: identifying relevant studies

Multiple key search terms were developed and used to capture the breadth of literature pertaining to how an infant experiences hospitalisation (Table 1). These were based on an infant's ability to utilise their senses to explore and experience the world around them, as well as routine infant activities (feeding, sleep) and their emotional needs (bonding, attachment, relationships, mental health). Paediatric intensive care was included in the literature search as young infants may be cared for as part of the general PICU population in some centres, however literature focusing on paediatric intensive care was limited to the neonatal age group only (less than 28 days of age or 44 weeks post-menstrual age at admission). All searches were limited to English language and from 2009 to current day to capture work that focuses on current neonatal care practices, given it is an ever-evolving field. The following electronic databases were searched: MEDLINE, CINAHL (Cumulative Index of Nursing and Allied Health Literature), PubMed and PsycINFO. In addition, manual searching of reference lists was undertaken to ensure identification of any other primary sources.

2.1.3. Stage 3: study selection

In accordance with scoping review methodology, the inclusion criteria aimed to capture studies which met our definition of the infant experience (i.e. reported infant's responses to the environment or daily activities and encounters via direct observation, paid attention to what the infant was conveying about their experience through their behaviours and communication, or reported carer's views of the infant's experience). Articles were excluded if they did not relate back to or focus on the infant's experience or if the authors focused only on the parental or clinician's personal account of their NICU experience. Review articles or studies that investigated an intervention within the NICU environment were also excluded. A summary of the search process is illustrated in Fig. 1.

Table 1
Search terms utilised in the literature search.

Hospital/physical environment	Study population	Components that influence an infant's experience of NICU
Neonatal intensive care, NICU, paediatric intensive care, PICU	Newborn, new-born, newborns, new-borns, baby, babies, neonate, neonates, infant, and infants	Light, vision, visual perception, sound, noise, auditory perception, smell, olfactory perception, touch, touch perception, touch sensation, pain, taste, taste perception, feeding, sensory deprivation, sleep, bonding, relationships, attachment, parent-relations, professional-patient relations, nurse-patient relations, physician-patient relations, stress, mental health, and patient satisfaction

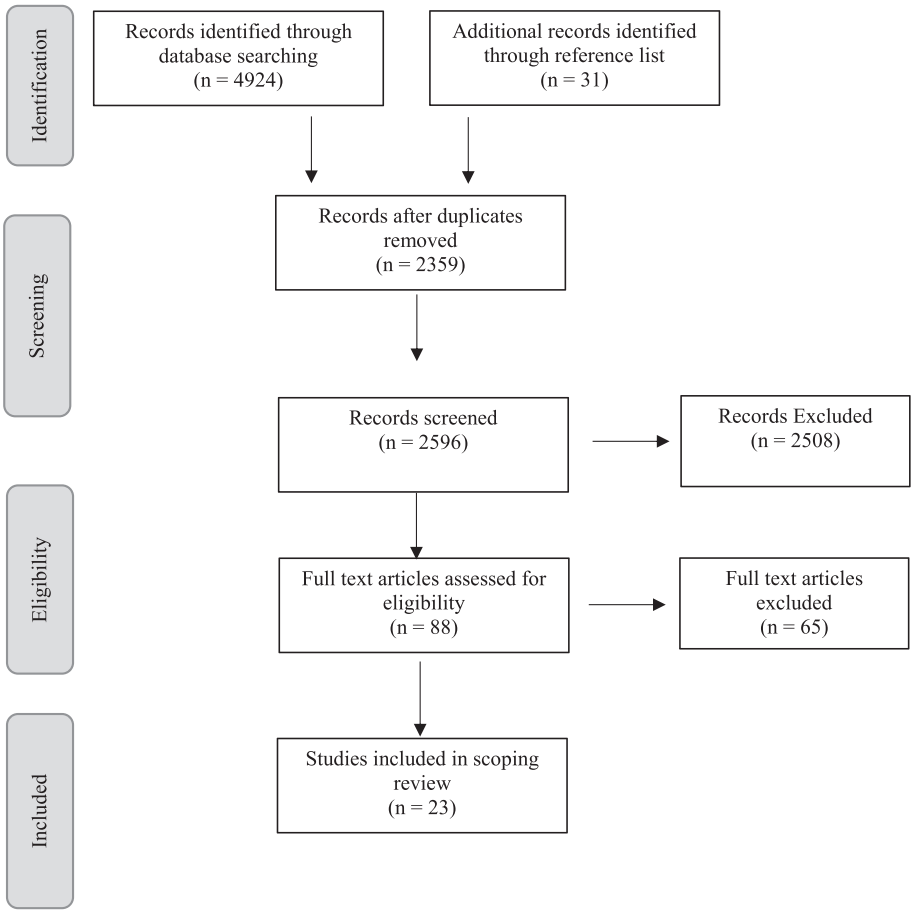

Fig. 1. Study selection flow diagram.

2.1.4. Stage 4: charting the data

In the fourth stage of the review, we charted data, recording pertinent information from eligible studies. Categories included for data extraction were as follows: (a) study demographics (author, year, country), (b) study population, (c) study objective, (d) study design, (e) data collection methods (i.e. how did the author collect data about the infant's experience), (f) key findings, and (g) author recommendations.

2.1.5. Stage 5: collating, summarising, and reporting results

The fifth stage of the review was the most intensive stage of the study where we analysed the data, reported the results, and applied meaning to these results.

3. Results

A total of 4955 articles were identified through database searching and other sources; 2359 duplicates were removed, and the review of the remaining titles and abstracts resulted in the exclusion of a further 2508 records. The most common reason for exclusion was a lack of focus on the infant's experience of NICU as defined by the study objective. Of the selected studies, 88 were submitted to a full text review, following which, 23 studies were deemed eligible for inclusion.

3.1. Study characteristics

Table 2 outlines the characteristics of the 23 publications included in this scoping review [30–52]. Participants included in the reviewed studies were infants born either prematurely (gestational age at birth <37 weeks) or at term gestation. Most of the studies (n = 19) focused solely on preterm infants. Thirteen studies are from the United States, four are European, two are from the Middle East, and four are from South America. Most studies (n = 22) used quantitative research methodologies with a variety of data collection methods and predetermined outcomes. The studies used physiological parameters (respiratory rate, heart rate, blood pressure, temperature, systemic oxygenation saturations, cerebral oxygen saturations), medical outcomes (weight gain, complications of prematurity), neurodevelopmental outcomes, and observations of infant behaviour to infer the infant experience. One study used qualitative research design utilising semi-structured interviews of staff within focus groups and thematic analysis to interpret their findings.

3.2. Study findings

3.2.1. The infant's sensory experience and their response to their physical environment

Seven studies explored the infants' sensory experience and two studies focused on their response to the physical NICU environment [30–38]. Three studies measured the infant's experience using physiological parameters alone [30–32]. Three studies combined physiological measurements with infant behavioural states to infer the infant's sensory experience [33–35]. Caskey and colleagues documented the infant's sound environment [36]. The two studies that focused on the physical NICU space used medical and neurodevelopmental outcomes, relating these to the infant's experience of hospitalisation [37,38].

Multiple studies reported that noise levels within NICU exceed recommendations, irrespective of time of day or location (open bay or single-family room) [30,33,34]. When exploring the infant's experience of sensory stimuli there was an associated stress response (increased heart rate and decreased respiratory rate, peripheral oxygen saturations,

Table 2
The infant's experience of NICU.

Study demographics (author, year, country)	Study population	Study objective	Study design	Data collection methods (i.e. how did the author collect data about the infant experience)	Key findings	Recommendations
The infant's sensory experience						
Sound in NICU						
Cardoso, Kozlowski, Lacerda, Marques and Ribas, 2015, Brazil	n = 61 (weight: 1000–2500 g)	To evaluate the physiological and functional effects resulting from the exposure to noise on low weight infants in incubators in NICU.	Quantitative research design: prospective, observational, exploratory, descriptive study.	Measurements: noise levels (both inside and outside the incubator during "noise" and "sleep" times), HR, SpO_2 and assessment of infant behaviour using the APIB scale.	– Significant increase in HR and decrease in SpO_2 observed during periods of higher environmental noise. – Infants exhibit behavioural change in response to environmental noise.	Instigate noise reduction programs within NICU.
Caskey, Stephens, Tucker and Vohr, 2011, USA	n = 36 (BW ≤ 1250 g)	To determine the sound environment of preterm infant and to test the hypothesis that's infants exposed to more adult language will make more vocalisations.	Quantitative research design: prospective cohort study	Measurements: digital language processor recorded the infant's sound environment: adult speech, child vocalisations, and background noise.	– Most of the sound an infant is exposed to is composed of monitor noises and background noise. – Language, either adult or infant, comprises a small percentage of the sounds to which infants are exposed. – Infant vocalisations are present as early as 32 weeks CGA. – Adult word counts per hour and infant vocalisations per hour increase significantly between 32 and 36 weeks CGA.	Infant directed language should be encouraged as part of neonatal care.
Kuhn, Zores, Pebayle, Hoeft, Langlet, Escande, Astruc and Dufour, 2012, France	n = 26 (GA at birth <32 weeks)	To investigate whether (i) VPIs hear nosocomial sound peaks that are 5–10 dbA and/or 10-15dBA above background noise, (ii) how do they physiologically react to this noise and (iii) does the noise alter infant well-being.	Quantitative research design: prospective observational study	Measurements: sound peaks, environmental sounds, HR, RR, SpO_2, rcO_2, and arousal states (using Prechtl's observational rating system).	– VPIs can detect sound peaks of as little as 5dBA above background noise. – The physiological response noted by VPIs in response to noise included increased HR and decreased RR, SpO_2, and rcO_2.	NICU should have strict criteria to protect infants from the deleterious exposure to noise.
Smith, Ortmann and Clark, 2018, USA	n = 3	To identify the types, rate, and levels of acoustic events that occur in NICU and their potential effects on infant physiological state.	Quantitative research design: descriptive study	Measurements: noise levels, documentation of acoustic events by observer (alarm noise, infant- generated noise, staff/family noise or transient events), RR and HR.	– No correlation could be made between acoustic events and infant physiological state.	Hospital systems should strive to incorporate developmentally appropriate acoustic stimuli into the infant's environment rather than solely focusing on the diminution of all sound.
Williams, Sanderson, Lai, Selwyn and Lasky, 2009, USA	n = 8 (BW < 1000 g)	To measure the correlation between NICU noise levels and ELBW neonate's HR and BP and to determine whether these correlations differ by BW.	Quantitative research design: descriptive, observational study	Measurements: noise levels, HR, and BP.	– The lower BW infants responded to noise events with significant increase in HR. – Higher BW infants experienced a biphasic response to increasing noise levels in NICU (deceleration initially followed by an acceleration in HR).	Reducing noise levels in the NICU may reduce stress for ELBW infants by improving physiological stabilisation in this vulnerable patient group.
Sound, light, and infant handling in NICU						
Peng, Bachman, Jenkins, Chen, Chang, Wang, 2009, Taiwan	n = 37 (GA at birth <36 weeks)	To examine the relationship between environmental stressors (light, sound, and handling) and biobehavioural responses in preterm infants	Quantitative research design: exploratory, descriptive study	Measurements: (i) physiological- HR, RR, and SpO_2, (ii) handling- a Likert scale was used to measure the degree of stimulation in nursing interventions, (iii) behavioural stress responses — sleep-wake	– There was a statistically significant relationship between environmental stressors (both light and sound) and changes in physiological state (increased HR, increased RR, and decreased SpO_2). – There was also a	Early recognition of physiological and behavioural stress responses in relation to environmental stressors is prudent to provide individualised patient care.

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Table 2 (*continued*)

Study demographics (author, year, country)	Study population	Study objective	Study design	Data collection methods (i.e. how did the author collect data about the infant experience)	Key findings	Recommendations
				states, self-regulatory behaviours, and behavioural stress cues.	statistically significant relationship between environmental stressors (light, sound, and handling) and some specific stress behaviours.	
Light in NICU						
Zores, Dufour, Pebayle, Langlet, Astruc, Kuhn, 2015, France	n = 27 (GA at birth <32 weeks)	To understand the response of VPIs to light variation in incubators.	Quantitative research design: prospective, observational study	Measurements: HR, RR, SpO_2 and rcO_2.	– VPIs react to moderate variations to light levels. – Significant increase in RR with mild variations to light levels (delta lux <50). – Significant increase in HR, RR and rcO_2 with larger variations to light levels (delta lux >50).	Preterm infants should be protected from variations in light exposure in NICU to protect physiological stability.
The infant's experience of the physical NICU environment						
Lester, Hawes, Abar, Sullivan, Miller, Bigsby, Laptook, Salisbury, Taub, Lagasse, Padbury, 2014, USA	n = 403 (BW ≤ 1500 g)	To determine whether SFR NICU layout is associated with improved medical and neurobehavioral outcomes.	Quantitative research design: longitudinal, prospective, quasi-experimental cohort study	Measurements: LOS, weight at discharge, CGA at discharge, rate of weight gain, HC at discharge, GA at full enteral feeding, rates of NEC, IVH, PVL, ROP, sepsis, supplemental oxygen use, CPAP use, mechanical ventilation, rates of BPD, assessment of neurobehavioural outcomes using NNNS and pain scores using Premature Infant Pain Profile. Maternal and staff questionnaires.	– Infants cared for in SFR had improved weight gain, reduced infection rates, few medical interventions, and faster transition to enteral feeds – Infants in SFR also demonstrated increased attention, less physiological stress, less hypertonicity, less lethargy, and reduced pain scores.	This study supports the move to SFRs in NICU to improve neurobehavioural and medical outcomes for hospitalised infants but also emphasises the importance of maternal involvement, staff collaboration and developmental support for preterm infants.
Pineda, Neil, Dierker, Smyser, Wallendorf, Kidokoro, Reynolds, Walker, Rogers, Mathur, Ven Essen and Inder, 2014, USA	n = 136 (GA at birth ≤30 weeks)	To evaluate associations between NICU room type (open ward and SFR) and medical outcomes: neurobehaviour, electrophysiology and brain structure at hospital discharge, as well as developmental outcomes at 2 years.	Quantitative research design: prospective, longitudinal cohort study	Measurements: rates of PDA, NEC, ROP, cerebral injury, confirmed sepsis, use of fentanyl, postnatal steroids or inotropes, days on TPN, maximum amount of oxygen, days of intubation, days of CPAP, hours of oxygen therapy, oxygen requirement at CGA 36 weeks, CGA at discharge, LOS. Neurobehavioural outcomes were measured using: Premie Neuro, NNNS, the Dubowitz Neurological Exam and the Neonatal Oral Motor Assessment Scale Additional measurements: aEEG monitoring, brain imaging (MRI).	– There was no difference in baseline or medical factors amongst infants in private rooms compared with open wards. – There was no significant difference observed in the neuro-behavioural scores between infants managed in private rooms versus open bay. – At term equivalent age, there was a trend toward having lower aEEG maturations scores for infants in SFRs. – At age 2 years, infants from SFR had lower language scores and a trend toward lower motor scores which persisted after adjustment for potential confounders.	Individualised, developmental care that encourages parental involvement should be encouraged in NICU. Further research is needed to explore the sensory stimulation infants are exposed to in private rooms.
The infant's experience of medical treatment						
Cong, Wu, Vittner, Xu, Hussain, Galvin, Fitzsimons, McGrath and Henrdson, 2017, USA	n = 50 (GA at birth 28–33 weeks)	To investigate the impact of early life painful/ stressful experiences on neurobehavioral outcomes of preterm infants in the NICU.	Quantitative research design: prospective, longitudinal study	Measurements: early life pain/stress using the NISS, parental contact using a bedside chart which noted the activity and the duration of the activity (recorded SSC,	– Preterm infants experienced a high degree of pain/stressors in the NICU, both in numbers of daily acute events and cumulative times of chronic/stress exposure.	Strategies to reduce both acute and chronic pain in NICU and increase positive experiences are essential to improve infant outcomes.

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Table 2 (*continued*)

Study demographics (author, year, country)	Study population	Study objective	Study design	Data collection methods (i.e. how did the author collect data about the infant experience)	Key findings	Recommendations
				breast feeding holding or cuddling, hand swaddling or touch, talking, singing, reading), neurobehavioural response data was collected at CGA 36–37 week using the NNNS.	– In comparison parental contact time was minimal. – Infants who experienced more daily pain/stressors and daily chronic pain/ stressors had worse neurobehavioural outcomes.	
Jeong, Park, Lee, Choi and Lee, 2014, Korea	n = 145 (all infants admitted to NICU were eligible)	To evaluate the painful procedures encountered in hospitalised infants.	Quantitative research design: prospective survey	Measurements: self-administered survey questionnaire relating to 27 painful procedures in NICU.	– An overall average of 105.6 painful procedures were performed per baby, with a daily average of 7.54 painful procedures and a weekly average of 25. – Oral suctioning was the most frequently performed painful procedure. – Infants born more prematurely and with a lower BW underwent more painful procedures.	Painful procedures should only be executed if deemed essential to patient care.
Orovec, Disher, Caddell and Campbell-Yeo, 2019, USA	n = 242 (GA at birth <37 weeks)	To report on neonatal pain exposure, pain management, and pain assessment/ documentation for a cohort of preterm infants during their hospital stay.	Quantitative research design: retrospective chart review	Measurements: procedure date and time, procedure type, pain scores, pharmacological and non-pharmacological interventions used, and number of attempts required for successful procedure.	– The 242 neonates included in the study underwent a total of 11,191 procedures. – Most common painful procedure was heel lance. – The frequency of painful procedures decreased over the course of the admission. – Only 32.6% of procedures had a documented pain score. – Sucrose was the most widely used pharmacological agent to manage pain. – Non-nutritive sucking was the most widely used non-pharmacological method to manage pain.	Increased efforts are required to promote consistent pain assessment and management to ensure optimal outcomes for vulnerable at-risk infants.
Pereira, Nogueira de Goes, Fonseca, Scochi, Castral and Leite, 2013, Brazil	n = 20 (GA < 37 weeks)	To describe the handling that preterm infants are subjected to over a 24-hour period.	Quantitative research design: observational, descriptive, exploratory study	Measurements: the type, frequency, duration of handling, and time the handling occurred.	– The 20 preterm infants underwent a total of 768 periods of handling and 1341 procedures in a 24-hour period. – The frequency of handling for each infant ranged from 14 to 71 episodes and the frequency of procedures ranged from 59 to 109 in the 24-hour period.	Careful consideration by clinical staff as to the appropriate timing of procedures and need for handling of preterm infants.
The infant's experience of relationships within NICU						
Pineda, Bender, Hall, Shabosky, Annecca and Smith, 2018, USA	n = 81, (GA ≤ 32 weeks	To (i) define predictors of parent presence, any holding, holding in arms, and SSC in the NICU and (ii) investigate the relationship between parent participation and (a) early neurobehaviour and (b) developmental outcomes.	Quantitative research design: oobservational, descriptive study	Measurements: parent presence, medical factors and socio-demographic factors were collated from the medical notes. NNNS and Dubowitz Optimality Scale were performed at CGA 35 weeks. At age 4 to 5 years the ASQ-3 was completed by parents.	– Parents were present an average of 4 days per week and held their infants an average of 2–3 days per week. – Infants whose parents held them more often had better short-term outcomes, with those who were held SSC demonstrating better	Parents should be encouraged to engage in infant care in NICU.

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Table 2 (*continued*)

Study demographics (author, year, country)	Study population	Study objective	Study design	Data collection methods (i.e. how did the author collect data about the infant experience)	Key findings	Recommendations
					short and long-term outcomes overall.	
Reynolds, Duncan, Smith, Mathur, Neil, Inder and Pineda, 2013, USA	n = 81 (GA ≤ 30 weeks	To investigate the effects of parental presence and infant holding in the NICU on neurobehaviour at term equivalent.	Quantitative research design: prospective, longitudinal, cohort study	Measurements: parental presence, NISS scores and NNNS scores.	– The mean hours per week of parent visitation was 21.3 ± 20.9. – Infants were held on average of 2.3 ± 1.5 days per week. – Over the hospital stay, visitation hours decreased, while holding frequency increased. – Parental visits and holding had a positive effect on infant neurobehaviour.	Neonatal staff should support early parent engagement in NICU care.
The infant's experience of feeding in NICU						
Pickler, McGrath, Reyna, Tubbs-Cooley, Best, Lewis, Cone and Wetzel, 2013, USA	n = 87 (CGA 30–32 weeks)	To examine the effect of the NICU environmental characteristics (levels of sound, light, time of day) in open wards and SFRs on oral feeding outcomes in preterm infants.	Quantitative research design: observational study	Measurements: time of day feed occurred, prescribed volume of feed and the volume consumed, infant's wakefulness prior to and at the end of feeding (simple yes/no question), and the nurse's perception of light and sound levels (using a 5-point Likert scale).	– Infant oral feeding was significantly improved by moderate light levels. – Oral consumption was negatively affected by the time of day (i.e. reduced oral intake at the busiest times of the day). – When infants were awake at the start of the feed, they consumed a greater proportion of the prescribed volume. – Infants consumed a greater proportion of their feed in the open bay setting.	Interventions should be put in place to minimise sound and light levels during infant feeding times. There is an ongoing need to train staff in the assessment of infant behavioural states to optimise successful oral feeding.
Tubbs-Cooley, Pickler and Meinzen-Derr, 2015, USA	n = 89 (GA at birth <32 weeks)	To examine the association between missed oral feeding opportunities amongst preterm infants with achievement of full oral feeding and LOS.	Quantitative research design: observational study	Missed oral feeding opportunities were documented by NICU nurses as unrelated to the infant's clinical condition or state of wakefulness at the time of the feed and instead categorised as missed due to "time-management reasons" or "other reasons". Once oral feeding was initiated, data was collected at each scheduled feeding time using a data collection form which allowed the bedside nurse to record a reason why an oral feed was not offered.	– 30 infants experienced one or more missed oral feeding opportunities. – Each 1% increase in the proportion of missed oral feeding opportunities extended the time to achieve full oral feeding by 1.45 days and time to discharge by 1.36 days.	Future research is needed to understand why preterm infants are missing oral feeding opportunities in NICU. If missed feeding opportunities are related to nurse workloads, then system-level interventions are required, which could include staggered staffing times around feeding schedules or policies and environments that promote parental presence and involvement in infant feeding for the duration of the hospital stay.
The infant's sleep experience in NICU						
Sleep and the physical environment						
Kuhn, Zores, Langlet, Escande, Astruc and Dufour, 2013, France	n = 26 (GA at birth <32 weeks)	To evaluate the impact of moderate noise on the sleep of VPIs.	Quantitative research design: observational study	Measurements: sound pressure levels and environmental sounds were recorded using a dosimeter. Arousal states were assessed using Prechtl's observational rating system.	– Moderate acoustic changes can disrupt the sleep of VPIs.	NICUs should employ sound control measures to protect infant sleep.
Orsi, Avena, Lurdes de Cacia, Tsunemi, Machado and	n = 12 (GA at birth <37 weeks and	To describe the impact of the NICU physical environment on infant sleep.	Quantitative research design: observational study	Measurements: infant sleep (PSG), noise levels, light levels, temperature levels and relative air	– Total sleep time for the infants observed in this study was 14.9 h. – Increased light levels	Strategies to promote and protect sleep by decreasing newborns' exposure to excessive

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Table 2 (*continued*)

Study demographics (author, year, country)	Study population	Study objective	Study design	Data collection methods (i.e. how did the author collect data about the infant experience)	Key findings	Recommendations
Pinheiro, 2017, Brazil	BW 1200–2000 g)			humidity. Infants were video recorded to observe handling by clinical staff.	resulted in increased periods of wakefulness.	light should be implemented in NICUs.
Zores, Dufour, Pebayle, Dahan, Astruc and Kuhn, 2018, France	n = 27 (GA at birth <32 weeks)	To determine whether small variations in light levels affect the sleep of preterm infants.	Quantitative research design: observational study	Measurements: arousal states were assessed during periods of different light exposure using Prechtl's observational rating system.	– VPIs can be woken by small variations in light, when the light protection in their incubator is insufficient.	Caregivers should protect vulnerable infants from the potentially deleterious effects of modest changes in light levels.
Caregiving and sleep						
Levy, Hassan, Plague, Sokoloff, Kushwaha, Chervin, Barks and Shellhaas, 2017, USA	n = 25 (GA > 35 weeks at birth)	To (i) determine the frequency and duration of hands-on-care and its impact on sleep and (ii) to assess the incidence of respiratory events associated with handling for a cohort of sick neonates.	Quantitative research design: observational study	Measurements: PSG-defined behavioural states, episodes of handling (direct contact with the infant or manipulation of their immediate environment) and physiological events (hypopnea, apnoea, oxygen desaturations).	– Handling of infants in NICU is frequent and administered across all sleep states, associated with both substantial sleep disruption and potentially consequential respiratory instability.	Strategies to protect sleep and minimise sleep-disordered breathing may improve neonatal outcomes.
Maki, Sbampato Calado Orsi, Tsunemi, Hallinan, Pinheiro and Machado Avelar, 2017, Brazil	n = 12 (BW 1200–2000 g)	To identify the types of procedural handling performed on preterm infants and its effect on infant sleep.	Quantitative research design: observational, correlational study	Measurements: total sleep time, active sleep time, quiet sleep time, wake time and episodes of handling (grouped into categories of monitoring, therapeutic/diagnostic, hygiene/comfort and feeding).	– The newborns were handled an average of 176.4 (±37.9) times during the 24-hour period. – The proportion of total sleep time was 57.2% in 24 h. – Single handling procedures had a strong positive correlation with wake time. – There was no statistically significant correlation between frequency or duration of handling on infant sleep.	Handling should align with the infant's sleep-wake-cycle to minimise disruption to infant sleep.
Clinician's perspective of the infant's experience within NICU						
D'Agata, Couglin and Sanders, 2018, USA	n = 17	To explore the NICU clinician's perceptions of the infant experience and how the terms trauma/traumatic would impact their clinical roles and practices.	Qualitative research design	Semi-structured focus groups interviews	– Clinicians expressed their perceptions of the infant experience as unpredictable, overstimulating, painful and stressful. – Reluctance to label the NICU hospitalisation as traumatic.	Making explicit the potential trauma of neonatal intensive care hospitalisation and the healing power of social connectedness empowers professional to provide evidence-based trauma-informed care practices.

Note: HR = heart rate, SpO_2 = oxygen saturation, APIB scale = Assessment of Preterm Infant's Behaviour Scale, BW = birthweight, CGA = corrected gestational age, GA = gestational age, VPI = very preterm infant, dBA = A-weighted decibel, RR = respiratory rate, rcO_2 = regional cerebral oxygenation, ELBW = extremely low birthweight, BP = blood pressure, SFR = single family room, LOS = length of stay, HC = head circumference, NEC = necrotising enterocolitis, IVH = intraventricular haemorrhage, PVL = periventricular leukomalacia, ROP = retinopathy of prematurity, CPAP = continuous positive airway pressure, BPD = bronchopulmonary dysplasia, NNNS = NICU Network Neurobehavioural Assessment scale, PDA = patent ductus arteriosus, TPN = total parenteral nutrition, aEEG = amplitude integrated electroencephalography, MRI = magnetic resonance imaging, NISS = NICU Infant Stressor Scale, SCC = skin-to-skin care, ASQ-3 = Ages and Stages Questionnaire-third edition, and PSG = polysomnography.

and cerebral oxygenation saturations) amongst infants when exposed to excessive light and noise [30,32–35]. No correlation was noted between NICU noise levels and infant blood pressure measurements [31].

Caskey and colleagues explored the natural sound environment of NICU [36]. They found that most sound infants are exposed to in the NICU comes from the surrounding technology and background noise. Language, either adult or infant, comprises only a small percentage of the sound infants hear on a day-to-day basis [36]. An infant's ability to communicate and participate in a conversation as measured by infant vocalisations and conversational turns was noted as early as 32 weeks gestational age. There was a positive correlation between parental presence and increased infant directed language and infant vocalisations. Spoken language was also significantly higher during feeding times, again showing a positive response from infants with an increase in infant vocalisations [36].

Lester and colleagues found single family rooms to have favourable outcomes for infants: improved weight gain, reduced infection rates, fewer medical interventions, faster transition to enteral feeds as well as reduction in physiological instability and infant pain scores, and more favourable neurobehavioural outcomes [37]. Lester and colleagues

relate these improvements to increased developmental support and maternal involvement when infants are nursed in single family rooms [37]. Pineda and colleagues however found no difference in medical or neurodevelopmental outcomes at the time of discharge from hospital between room types. They hypothesise that their finding of poorer neurodevelopmental outcomes at 2 years of age for infants nursed in a private room may be attributed to the relative sensory deprivation associated with private rooms, particularly in an urban American NICU setting with low parental visitation rates, leading to reduced language exposure and caregiver contact [38].

3.2.2. The infant's experience of medical treatment

Four studies explored the infant's experience of medical treatment via descriptive studies with quantifiable outcome measures to depict the infant's experience of clinical care [39–42]. Pereira and colleagues used video recordings to examine the types of handling experienced by preterm infants over a 24-hour period in NICU [39]. They reported 768 periods of handling and a total of 1341 procedures. The frequency of handling for each infant ranged from 14 to 71 episodes and the frequency of procedures ranged from 59 to 109 in the 24-hour period [39]. The authors question the necessity of such burdensome handling on the developing infant and recommend tighter adherence to developmental care protocols ensuring the grouping of handling activities and dedicated rest periods for infants [39].

The three articles exploring infant pain in NICU acknowledge the significant exposure to pain and stressful procedures encountered by hospitalised infants during a critical period of brain development [40–42]. Jeong and colleagues studied the first 2 weeks of an infant's admission to hospital using a predetermined checklist of 27 painful procedures [40]. During the studied timeframe they reported an average of 105.6 painful procedures performed per baby, with a daily average of 7.5 painful procedures. In their study, suctioning was the most common painful procedure [40]. Cong et al. investigated whether premature infants born between 28 and 32 + 6 weeks gestational age, subjected to stressful early experiences during their first 4 weeks of hospitalisation would develop an altered neurodevelopmental outcome at 36–37 weeks corrected gestational age [41]. They utilised a validated instrument, the NICU Stressor Scale (NISS), to provide a cumulative measure of infant's exposure to both acute stressful procedures (numbers), such as heel lancing, and chronic stressful exposure (h) such as an indwelling nasogastric tube [41]. During the first 4 weeks of their NICU stay, infants on average experienced a total of 643.2 ± 64.5 acute procedures with a daily average of 23.0 ± 2.3 procedures. There were 1192.5 ± 420.5 h of chronic events with a daily average of 42.6 ± 15.0 h (some infants encountered several chronic procedures at the same time, and since a cumulative hour score was calculated the daily duration of chronic events exceeds 24 h). In comparison parental contact time during the first 4 weeks of hospitalisation in this study was deemed insufficient (skin-to-skin care provided by mothers averaged 13 min daily and fathers 1 min daily) [41]. Using the validated Neonatal Intensive Care Unit Network Neurobehavioural Scale (NNNS) infants underwent neurobehavioural testing at term corrected age. The study concluded that infants who experienced more daily pain/stressors had poorer neurobehavioural outcomes at term corrected age [41]. Orovec and colleagues conducted a retrospective chart review of neonatal pain exposure, pain management, and pain assessment and documentation, for a cohort of preterm infants' entire hospital admission [42]. The 242 infants underwent a total of 10,469 painful procedures (4801 tissue breaking and 5667 non-tissue breaking, with only 56.6% and 12.2% respectively, having a documented pain score) [42]. In this study, heel-lancing was the most common painful procedure. The authors noted that the frequency of painful procedures decreased over the course of the infant's admission. Sucrose and non-nutritive sucking were the most common methods employed to manage pain [42]. All three articles echo the recommendations set out by Pereira et al., calling for the careful consideration of the necessity of handling and painful procedures and, when deemed necessary the appropriate use of pain assessment tools, pain management strategies and parental involvement in care to mediate the cumulative stresses of pain and handling in NICU [39–42].

3.2.3. The infant's experience of relationships within NICU

Two articles reported on parental presence within NICU as a means of inferring the infant's experience of relationships with primary caregivers [43,44]. Pineda et al. found that the median number of days per week a parent was present in NICU with their infant was 4 days. Infants were held by their parents a median number of 2.8 days per week [43]. They also reported on predictors of parental presence on the neonatal ward. More parent participation was observed amongst mothers who were Caucasian, married, employed, or older, and those who had familial support, fewer children, or provided breast milk. Increased parental participation was also observed for infants with fewer medical complications [43]. In this study there was a demonstrable improvement in neurobehavioural outcomes for infants who experienced more holding [43]. These findings were echoed by Reynolds et al. who found a positive correlation between the amount of parental contact and holding and neurobehavioural outcomes [44]. In their study, infants were held on average 2.3 ± 1.5 days per week [44]. Both studies highlight the importance of engaging parents to actively participate in the care of their infants during their hospital stay.

3.2.4. The infant's experience of feeding in NICU

Two articles discussed the infant's experience of feeding in NICU [45,46]. Pickler and colleagues describe the adverse effects exerted by the NICU physical environment on infant feeding and showed that, by reducing light and sound levels and responding to infant feeding cues of readiness to feed, feeding outcomes improve [45]. They also commented that rates of infant feeding were lower during the busier times of day in NICU (i.e. working daytime hours) [45]. Infant characteristics also impacted infant feeding; in this study female infants consumed more than males, healthier infants consumed more than sicker infants, and mature infants consumed more than less mature infants [45]. Tubbs-Cooley et al. in their work explored missed feeding opportunities in NICU revealing that infants who missed out on the experience of oral feeding, despite infant readiness, took longer to achieve full oral feeding and remained in hospital for longer [46]. Both articles recommend the early engagement of parents in neonatal care, especially their active participation at infant feeding times.

3.2.5. The infant's sleep experience in NICU

Five articles describe infant sleep in NICU [47–51]. Three articles explore the impact of sensory stimuli from the NICU environment on sleep, hypothesising that the physical NICU surroundings: bright lighting, high ambient noise levels, frequent alarms, and absence of day-night differentiation in combination with the frequency of interventions and handling for neonatal care, disrupt infant sleep [47–49]. Kuhn et al. evaluated the effect of moderate noise on the sleep of very preterm infants by observing infant behavioural states [47]. They reported that preterm infants are repeatedly exposed to sound pressure levels that exceed recommendations and that repeated and atypical noise is harmful to infant sleep [47]. Using infant observation, Zores and colleagues explored the impact of light on infant sleep. Their study found that small light-level increases led to sleep disruption in very preterm infants [48]. Orsi and colleagues used polysomnography (a non-invasive test considered the gold standard for sleep assessment) to determine how the physical NICU environment, its noxious stimuli and infant handling influenced sleep [49]. The preterm infants studied showed a mean total sleep time of 14.9 h within the 24-hour period. This work again demonstrated that infants are exposed to sound levels greater than that specified by regulatory bodies [49]. However, in this study the sound levels did not influence infant sleep, explained perhaps by the habituation phenomenon, which is characterised by an infant's capacity to diminish his/her behavioural responses when exposed to

frequent and repeated stimuli [49]. The results did show that wakefulness time increased with increasing light levels within the incubator and that the more the infants were handled the more time they spent awake [49].

Using polysomnography, two articles focused on infant handling and its impact on sleep. Levy and colleagues showed that all infants underwent frequent handling [50]. The total duration of hands-on care lasted an average 65.3 ± 33.0 min, or 27% of the 4-hour polysomnography [50]. Contacts were most often initiated for clinical care and were initiated across all behavioural states. They also examined the physiological response of infants to handling during sleep. They found that handling was frequently followed by respiratory events: hypopnoea, apnoea, and desaturation occurred within 60 s on 16%, 8%, and 19.5% of all contacts, respectively [50]. Maki and colleagues also demonstrated high frequency of handling: an average of 176.4 (±37.9) times during the 24-hour period. In this study the proportion of total sleep time was 57.2% in 24 h [51]. There was no statistically significant correlation between frequency or duration of handling and the sleep of preterm infants [51]. Recommendations from these articles include creating an environment that promotes and protects infant sleep. Authors also encourage formal staff training in the assessment of infant sleep-states and behaviour so that routine care is infant-led and cue-based [47–51].

3.2.6. Parent and clinician perspective of the infant experience of NICU

No articles discussed parental opinion of the infant's journey through NICU. One article was identified that reported on clinicians' perspective of the infant's experience of NICU. In their qualitative analysis D'Agata and colleagues explored the terminology that best describes the NICU infant experience, through focus group discussion with neonatal healthcare providers [52]. During these focus groups they proposed the use of the word "traumatic" to describe the infant experience. Emergent themes from the focus groups describe the fragility of the infants, parents, and clinicians themselves in the NICU environment [52]. While clinicians expressed their perceptions of the infant experience as unpredictable, overstimulating, painful, and stressful, they were reluctant to label these early lived experiences as traumatic [52]. Hesitations relate to the clinicians' personal concerns that they may be the agents of trauma and the potential negative impact on the already vulnerable families by labelling the admission as traumatic [52].

4. Discussion

Stressful early life experiences in the NICU continue to be an inherent part of the high-technology, lifesaving care for hospitalised infants [41]. The course and length of the NICU experience has been found to be one of the most crucial factors influencing infant neurodevelopment and health outcomes; particularly because this is a modifiable factor that occurs during a critical period of neurodevelopment [53,54].

This review, which aims to interrogate the literature for knowledge of the NICU experience from the infant's perspective, affirms the link between noxious stimuli and the infant stress response both physiologically and behaviourally [30–35,37,38]. Despite environmental guidelines and recommendations, the environment is repeatedly described as too loud and too bright, impacting on physiology, infant behaviour, sleep, feeding, and neurobehavioural outcomes [30–35,37,38,45–49].

Sleep is essential for normal health and development in children. Alterations in sleep can have a negative impact on behaviour and may result in cognitive impairment [55,56]. Disturbances in neonatal sleep have been associated with increased distractibility in later childhood [57]. Disruption of sleep duration and quality in hospitalised patients has been described both in adult and paediatric populations, with patients treated within the intensive care unit setting showing the most profound sleep abnormalities [50]. Despite this there are limited available data on infant sleep in NICU. The five articles described in this review highlight the negative impact of hospitalisation on infant sleep [47–51]. Sleep is yet another aspect of an infant's early life experience which is disrupted with possible long-term implications. More research both acutely and with longer-term outcome data is required to investigate infant sleep in NICU.

Other research highlights an imbalance between negative handling for medical care and positive touch and interaction with caregivers [39–44]. These findings again question a lack of dissemination and implementation of family- and infant-centred models of care.

On one level, this review has identified multiple articles relating to the infant experience of NICU, recognising the negative effects of such an invasive experience for infants. However, when closely analysed, the studies have not focused on trying to understand these experiences from the infant's perspective, and neonatal research utilising qualitative methodologies is scarce. Shrouded by both pathology and technology, the infant as a real person can be lost both in the medical quest to save their life as well as in the literature. The infant too often being the object of research instead of an active participant.

This response from a neonatal clinician captures, openly and honestly, the complexity of the modern NICU.

"*We've all experienced the days where you almost just want to run and put your head in a corner because it's just… there's just stuff going on everywhere. Bells and whistles and alarms and beeping and people…ah! And it's like I can't imagine what these little babies are feeling like…* (**MD**)" [52].

A growing body of literature describes the physical NICU environment and the multiple stressors it exerts on the developing infant, implicating the environment as an independent risk factor for poorer developmental outcomes. Perhaps more importantly however, this review highlights the gap within neonatal literature, understanding the essence of the infant's experience by relying on an openness to explore this experience from the infant's perspective.

While infants may not be able to verbalise their experience, they can be "heard" if researchers are willing to utilise other methods of data collection. For example, the Newborn Behavioral Observations (NBO) System is an infant-focused, family-centred relationship-based tool, designed to highlight the full richness of a newborn infant's behavioural repertoire and communication style [58]. The NBO consists of 18 neurobehavioural observations and is designed for use from birth through the third month of life. These items are designed to show that newborn infants possess a wide range of visual, auditory, and perceptual abilities that allow them to explore the world around them and to engage in face-to-face, eye-to-eye mutual exchange [58]. The infant's behaviour is at the centre of the NBO with the clinical focus on the infant's individuality. Through observation and interaction, the NBO allows infants to fully show who they are: their preferences, capacities, and vulnerabilities. In other words, the NBO provides the infant with a "voice" and the baby as a developing person is revealed [58].

Despite the repeated message for healthcare providers to recognise and promote parents as the experts in their infant's needs, their opinions of the infant's experience have not been reported in the literature. D'Agata and colleagues are the first to investigate the clinician's perspective of the infant experience. They propose a conceptual model of infant medical trauma in the NICU (IMTN) that facilities an interdisciplinary approach for studying the infant's experience [8]. We suggest exploring the infant's lived experience through a qualitative lens to provide a rich description and complete picture of life in NICU.

4.1. Limitations

The results reported here are subject to certain limitations. Our emphasis in this scoping review was to examine the infant's experience of hospitalisation and therefore, we excluded any work conducted retrospectively following discharge from hospital. We also discounted systematic reviews and intervention studies. Despite these limitations, the results of this review highlight the need for hospital systems to foster an environment more in tune with the individual needs of the infant, strongly encouraging and facilitating parental involvement wherever possible.

5. Conclusion

This scoping review aimed to explore the lived experiences of infants hospitalised in neonatal intensive care. The studies captured in this review focused on quantitative, measurable outcomes as a proxy for the experience as it might be felt, interpreted, and processed by an infant. Much is known about the effects of the environment on the developing infant, but little research has sought to understand the experience from the infant's perspective. By employing qualitative methodology to explore the lived experience of infants in NICU the baby becomes an active agent in research and the process of data collection is modelling (and based on) a fundamental orientation to the baby's interpretation and response to stimuli. Collecting data "on" the baby may in effect be perpetuating an essential problem or gap in neonatal research: the baby as a subject not a person actively involved with their own voice and story to tell. Future qualitative studies would add an increased understanding of the lived experience of infants hospitalised in NICU and give greater descriptive meaning to the quantitative data already published.

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Natalie Duffy: Supervision, Conceptualization, Investigation, Formal analysis, Writing - original draft, Writing - review & editing. **Leah Hickey:** Conceptualization, Investigation, Validation. **Karli Treyvaud:** Conceptualization, Investigation, Validation. **Clare Delany:** Conceptualization, Investigation, Validation.

Declaration of competing interest

None declared.

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