



A study of the infant's lived experience of neonatal intensive care

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ABSTRACT

Background: Neonatal care is essential for survival. However, advancements in medical care may come at a cost to the infant's experience of living. Research has traditionally focused on the effectiveness of the medical aspects of neonatal intensive care. Less attention has been paid to the subjective experience of infants hospitalised in NICU. **Aim:** To provide an infant-centred, rich understanding and comprehensive analysis of the lived experience of infants hospitalised in NICU.

Methods: To explore the infant experience, we designed a novel approach, termed 360-degree phenomenology. We utilised observational fieldnotes, bedside diaries, Newborn Behavioural Observation recording forms and verbatim transcripts from individual interviews. Thematic analysis was used to analyse these data sources.

Results: This paper uses the whole data set (comprising a series of 7 case studies) to describe 4 overarching themes: (1) scary and safe; (2) all these hard things; (3) an emotional challenge; and (4) moments of meeting.

Conclusion: Hospitalisation in the newborn period poses a significant challenge to the developing infant by virtue of the complex and confronting early life experiences they endure, both physically and emotionally. This research illuminates these challenges but also shows moments of powerful meeting and connection, that serve to protect and nurture the developing infant. By listening to and valuing the infant's unique perspective and placing the infant as a person central to their own care, our research highlights strategies for immediate actionable change and future areas of research to better their early life experiences and improve long-term health outcomes.

1. Introduction

For infants with life threatening illness neonatal intensive care is essential for survival. However, the scope and nature of medical care required to achieve such outcomes may come at a cost to the infant's quality of life. Infancy (from birth to 12 months) is a unique time of rapid growth when the brain develops in ways that affects health and wellbeing across the individual's lifespan [1]. Infant mental health, meaning an infant's social, emotional and cognitive wellbeing, is primarily concerned with how infants experience the world [2]. Secure, loving relationships and positive early life experiences in infancy are

crucial components required to establish a favourable developmental environment for optimal health outcomes [3]. When an infant is admitted to the neonatal intensive care unit (NICU) there is an unavoidable disruption to these ideal experiences. Infants and their families must adapt to the hospital environment and the challenges this entails [4]. This stress, during a formative stage of development, may have lasting effects on physical, cognitive and social-emotional development [5–10].

Given this established link between the importance of early life experiences and future health outcomes there is increasing interest in understanding and documenting the infant's experience of neonatal care

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and the personal challenges they face. However, to date, no published work has sought to capture a sustained observation of the hospital experience from the infant's perspective. Instead, as our recent scoping review highlights, most studies have used quantitative, measurable outcomes as a proxy for how the infant might feel, interpret, and process their experiences [11]. This omission may be attributable to the perceived lack of methodologies and data collection techniques that can be utilised with this preverbal patient group.

The word "infant" derives from the Latin *infans*, meaning unable to speak. However, over the last 70 years, we have learned much about the behavioural repertoire of the newborn infant. Infants use intentional behavioural cues as their means of communication, to express their thoughts, feelings and experiences. Some of these cues are clear and unambiguous, open invitations to interact and engage or to move away and disengage, whilst others can be more subtle [12]. For example, an infant's language can be as clear as a loud cry ("help me") or as elusive and fleeting as a puckering of the brow to indicate slight displeasure ("this interaction is a little too intense for me"). It can be a bright-eyed look ("this is interesting") or a faint change of facial colour ("I'm slightly stressed, please give me a short break") [12]. These signals are the infant's means of communication, conveying messages, which provide information on how the infant may be feeling and what caregiving is required [12].

Utilising a variety of methods and observational tools, clinicians and researchers alike have demonstrated that infants are born with a sense of self and a sense of others and possess an inherent capacity for engagement, reciprocity, exploration, and discovery [13]. However in depth study of an infant's subjective experience of hospitalisation in NICU has been overlooked. Therefore, armed with this knowledge, this innovative study breaks new ground by centering the infant's experience through multiple perspectives: those of the infant, adult caregivers (parents and healthcare providers), and the researcher, elevating the infant as an active participant in neonatal research, giving infants a *voice* in matters that directly affect them [14]. Through our methodology, 360-degree phenomenology, we use a combination of close observation and documentation of an infant's responses to their NICU environment triangulated with the observations and interpretations of their adult caregivers to respond to the research question: what are the early lived experiences of infants hospitalised in NICU?

2. Methods

2.1. Study design

The roots of phenomenology are found in the epoch of Plato, Socrates and Aristotle but it was the subsequent work of Edmund Husserl, a German philosopher (1859–1938) who established phenomenology as an approach to study the lived experience of human beings at the conscious level of understanding [15]. Phenomenological studies, rooted in philosophy, focus on describing and understanding human experiences as they are lived, emphasising the subjective nature of these experiences [16]. Lived experience, therefore, is a representation and understanding of how a person encounters and interacts with the world around them [17]. It privileges the experience of the person undergoing an event, valuing the insights and learnings that only that person can offer [17]. The goal of phenomenology is to describe the meaning of these experiences-both in terms of *what* was experienced and *how* it was experienced [18]. For the purposes of this research, the *lived experience*, defined in phenomenological terms, are the infant's everyday first-hand encounters and interactions within the NICU environment and their response to these experiences [14].

2.2. Setting and participants

The study was conducted on a quaternary neonatal unit, in Melbourne, Australia, with 35 beds and approximately 800 admissions per

year, caring for infants with complex medical and surgical conditions. Most infants (>75 %) cared for on this unit are born at term gestation (≥ 37 weeks gestation) with the average length of stay being 18 days, however infants with complex pathology can spend months in NICU. The NICU has a recognised family-centred model of care with dedicated bedside support and online parent resources.

We used purposive sampling to recruit NICU patients, their primary caregivers and associated healthcare providers. To reflect the predominant infant population, infants were eligible to participate if they were born at term gestational age with an expected minimum length of hospital stay of >7 days. Exclusion criteria included preterm infants (the preterm population cared for by this specific NICU have encountered surgical complications of their extreme prematurity and as part of recognised developmental care practices are often housed in fully or partially covered incubators impeding direct observation), infants with congenital heart disease requiring surgery (these infants are co-managed between two hospital departments) or infants on a palliative care pathway. Infants were enrolled following written, informed consent by their primary caregivers. Primary caregivers also provided consent for their participation in interviews at two distinct time points in their infant's hospital journey. For each infant, key healthcare providers also provided consent to participate in semi-structured interviews. Infants participated in the study for their entire hospital admission or for a maximum of 12 weeks.

The study was led by a consultant neonatologist (ND) with additional qualifications in observing and understanding infant behaviour. Of note, she held no clinical responsibilities for the medical care of the infants recruited to the study. Ethics approval was obtained from the hospital's Humans Research Ethics Committee (HREC number 68973).

2.3. Data collection

Data were collected from April 2021 to January 2024. Holding the infant experience at the centre of this research (Fig. 1), through our 360-degree phenomenological approach, we utilised every possible lens to gain insight into the infant's experiential lifeworld [14]. We began with the infant, drawing on what the infants themselves communicated, observing and sharing in their hospital journey and then triangulated this with qualitative interviews with their significant adult caregivers. These different data sources provided a further perspective of the infant's lived experience. This methodological triangulation also increased the internal validity of the study (i.e. the extent to which the method is appropriate to answer the research question and the trustworthiness of the research findings) [19–23]. Data collection ceased when no new perspectives were being introduced from the data sources [24].

• Infant observation

Informed by the Tavistock Model of Infant Observation we conducted direct participant observation sessions at the infant's bedside [25]. Immediately post each observation session ND wrote thorough notes on what was seen from the beginning to the end of the observation session, with these fieldnotes forming raw data suitable for analysis. We aimed in these sessions to build a complete and empathic understanding of an infant's collective real time experience of everyday life in NICU. The goal being to describe in concrete terms, the infant's behavioural responses to the NICU environment and to catalogue their daily activities, interactions, and developing relationships. The observation sessions (minimum duration 30 min) were designed to occur at random time points for each infant recruited to the study to capture their varied experiences and to avoid always being present at a certain time point which may coincide with the same activity. There was no set minimum number of observation sessions with each infant, instead the principal researcher made every effort to spend as much time as possible with each participant. This ranged from a minimum of five observation

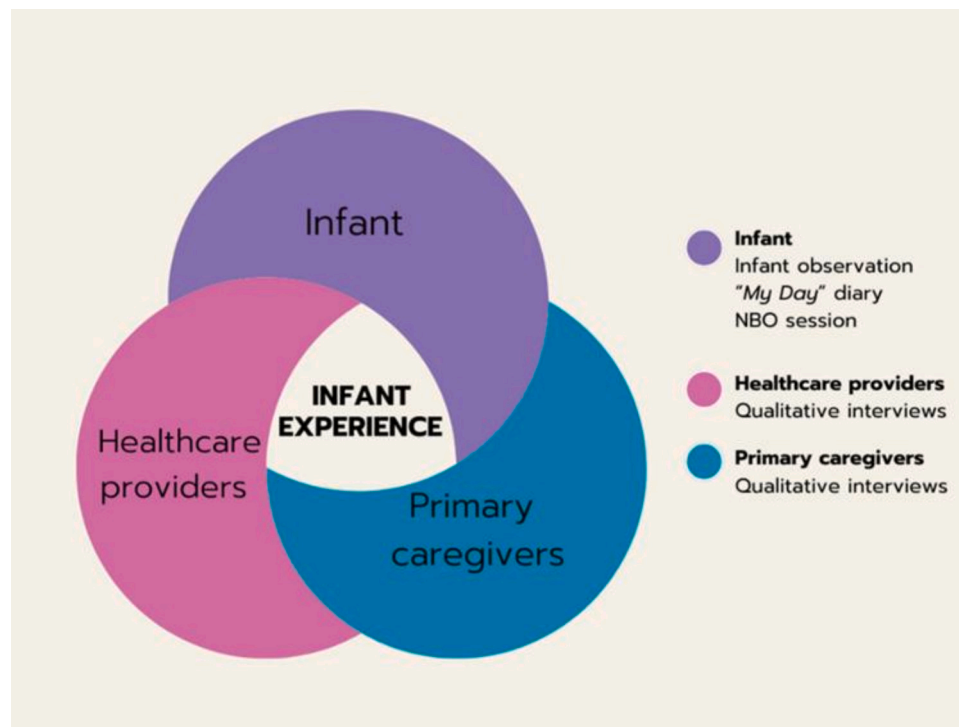


Fig. 1. 360-degree phenomenology and data collection methods.

sessions with one infant to as many as twenty-two with another. This disparity was due to variations in lengths of hospital stay for individual infants.

- “My Day” “diary”

To complement what was observed at the infant’s bedside we utilised bedside diaries as another method of capturing a snapshot of “a day in the life of an infant in NICU”. Any adult caregiver interacting with the infant was encouraged to contribute to this weekly 24-h bedside diary. The diary detailed time spent with family and medical and/or nursing caregiving interactions, for example skin-to-skin care, medical procedures such as intravenous access or nursing interventions such as nasogastric tube insertion. For ease of completion the diary included a predetermined list of common NICU activities as well as space for free text. Despite these pre-populated lists, the purpose of the bedside diaries was not to count these activities and apply statistical analysis rather it was to add more depth to the observational data and increase the “amount of time” the experience was under observation.

- Newborn behavioural observation (NBO) sessions

The NBO is an infant-focused, family-centred, relationship-building tool, designed to highlight the full richness of a newborn infant’s behavioural repertoire [26]. Weekly NBO sessions permitted direct interaction between ND, the infant, and their parents, allowing the infant to showcase their individuality and the opportunity to explore, fine-tune and add greater descriptive meaning to behaviours already observed at the infant’s bedside. The 18 items included in the NBO focus on the infant’s motor system including quality of movements, tone, and activity level; capacity for self-regulation (including crying and consolability); response to stress; and visual, auditory, and social-interactive capacities [26]. As is standard practice at the end of a NBO session ND and the parents reflected on the infant’s behaviours and completed a summary form in the *infant’s voice* detailing their behavioural cues, the strengths the infant exhibited via their behaviours and their caregiving needs. These “recording forms” were then used as

another observation source or “fieldnote” for thematic analysis.

- Qualitative interviews

Private interviews with the infant’s primary caregivers and members of their healthcare team were also conducted. In line with the exploratory aims of the study, adult caregivers were invited to provide their opinion and perspective of what they believed the infant was experiencing during their hospital admission. We explored their physical experiences and encounters and sensitively encouraged interviewees to reflect on how the infant might be thinking and feeling in the moment. All interviews were audio-recorded and transcribed verbatim by ND for analysis.

2.4. Data analysis

Data analysis occurred concurrently with data collection and involved two distinct phases guided by the principles of Braun and Clarke’s thematic analysis [27]. Firstly, an *in-case analysis* was performed (a case was defined as all data that one individual participating infant generated, i.e., observational fieldnotes, bedside diaries, NBO recording forms and interview transcripts) [28]. The authors independently read and formulated ideas pertaining to one case and then met to develop a coding scheme. This initial coding scheme aimed to describe and capture the key patterns and ideas of what was observed and said. This was then applied to the other cases, expanding upon the ideas, with regular meetings to discuss the data and resolve any discrepancies. We then conducted the second phase of data analysis, a *cross-case analysis*, which involved looking for recurring patterns of behaviour or interpretations across the entire data set to fully capture the lived experience of infants hospitalised in NICU [28]. Collated codes were then organised into themes. Rigour and reflexivity were maintained through prolonged engagement with the data and robust discussions during research meetings. Data were securely managed using a combination of hard copy and Microsoft Office 365.

3. Results

3.1. Participants

The total sample included 7 individual case studies comprising 7 infants, their parents and members of their healthcare team, see Table 1 for further sample characteristics. The 360-degree data sources included 73 infant observations sessions, 17 bedside diaries, 11 NBO sessions and 40 interviews. The amount of data generated per individual case study varied in relation to the infant’s admission length.

3.2. Key themes

We identified four key themes: (1) scary and safe; (2) all these hard things; (3) an emotional challenge; and (4) moments of meeting. Please note that throughout the results section, we have used pseudonyms to maintain participant confidentiality.

1. Scary and Safe

This theme encompasses the inherent tension of the NICU experience - NICU is both the ultimate “safe space” because a child’s life is saved by neonatal care, but it is also “scary and unknown” and “foreign and hostile” in many other ways (Table 2). One mother commented:

“I get that it’s keeping him alive, but do they need to keep him alive like this?” (mother 7).

The notion of NICU being a “safe space” was found in the recognition and acceptance of the need for medical care and intervention. As depicted in Table 2, the “scary” aspect of this theme reflects both observed moments and the many comments about the nature of the NICU environment. The following eloquent description, which echoes the point of view of many of those sharing in the infant’s journey, highlights the complexity of the NICU environment:

“If you don’t come in here, I don’t think you can fully understand just how overwhelming it is and just, you know, the pressure and the toll. Yeah, it is just a whole other world.” (mother 6).

Table 1
Sample demographics.

Sample demographics	
Infant Characteristics (n = 7)	
Gender	Male 4 Female 3
Reason for admission	Medical 2 Surgical 5
First child v. subsequent child	First child 6 Subsequent child 1
Admission length	<30 days 4 >30 days 3
Primary caregiver characteristics (n = 13)	
Primary caregiver interviews*	Mother 9 Father 7
Healthcare providers (n = 24)	
Role**	Number of staff members
SMS	3
JMS	8
NICU nurse	6
SCN nurse	1
Allied health professional	2
Senior surgical staff	2
Junior surgical staff	2

* Parents were invited to attend 2 private interviews, but this varied based on admission length.

** SMS = senior medical staff, JMS = junior medical staff, SCN = special care nursery.

Table 2
“A scary and a safe place”: examples from the data.

Data source	Primary caregivers	Healthcare providers	Observation reflection
Observing the infant	Primary caregivers	Healthcare providers	Observation reflection
Everything is alarming, there are people everywhere, all working to stabilise her.	“It is a scary and safe place.” Mother 4 “We are trying to make it as engaging for her as possible but left bare it’s a little bit clinical and there is not a lot to engage or stimulate her. It’s sort of more about what does she need medically, rather than sort of, her experience.” Father 5 “She’s surrounded by lots of beeping, lots of noises, lots of people. A lot going on.” Father 5	“It’s a flurry of activity in there with lots of interruptions and painful, I suppose for some babies.” JMS 4 “...just look at the colours in the room, the sounds, none of it, no one has said let’s build this room so that it is advancing development and then undo bits as required to meet medical needs. It’s the other way around. They’ve put all the medical stuff in and then we put a little bit of black and white somewhere, on a laminated cardboard, and then say, yeah, it’s good. It is substandard.” Senior surgical staff 1 “She is in a unit, with a breathing tube in her mouth, down her throat. Her room is filled with alarms. If she’s lucky she gets a bit of sunlight. She is surrounded by people, always talking around her about things that probably don’t make sense to her, rather than having what a normal baby should be having; time with her family, uninterrupted and growing.” SMS 1	I think, as a neonatologist, I may have stopped seeing or noticing the ward, because to me it is where I work, but now as a researcher, immersed here, I see it, I hear it, I smell it. All of it.
Observation Session	Primary caregivers	Healthcare providers	Observation reflection
Case study 3	Primary caregivers	Healthcare providers	Observation reflection
David is alone in his room, lying on his back in an open cot, wearing only his nappy. He is surrounded by machines and monitors, most of which are making some sort of electronic buzzing sound; medical equipment touches his body.	Primary caregivers	Healthcare providers	Observation reflection
Observation Session	Primary caregivers	Healthcare providers	Observation reflection
Case study 7	Primary caregivers	Healthcare providers	Observation reflection
The monitor is alarming, so too is the ventilator. The suction equipment gurgles as it is passed down the breathing tube. He is rendered silent by the breathing tube but his posture, his frown, his colour, all portray his feelings.	Primary caregivers	Healthcare providers	Observation reflection
Observation Session	Primary caregivers	Healthcare providers	Observation reflection
Case study 4	Primary caregivers	Healthcare providers	Observation reflection

NICU is filled with strange and loud noises, bright lights, complex technologies, a host of clinical personnel and sudden and unpredictable interruptions and disturbances (Table 2), all of which play a key role in the infant’s experience. The tension was further amplified when interviewees discussed the infant’s developmental surrounding (Table 2). There is a stark contrast between the expected nurturing environment of home and the “artificial life support” within NICU. One mother commented:

“It’s just so far removed from what she would be experiencing if she was at home.” (mother 3).

Again, as evidenced in the following quote, there is acceptance of the situation but longing for something different:

“As good as it is here, it’s not home.” (father 3).

The infants responded to the environment by showing discernible autonomic instability and dysregulated behaviours (Table 2). One interviewee commended the infants for the effort they make to adjust to their surroundings but also acknowledged the cost of this effort:

“They do a really good, amazing job, actually, of adjusting to the environment as best they can but, you know, when you are that small and trying to learn everything about the world, you don’t want to have that extra adjustment to do, it must be quite exhausting for them.” (allied health professional 2).

2. All these hard things

Amplifying the tension of our first theme, our second theme aims to capture all the things that happen to an infant on their NICU journey, their reaction to these events as well as the reaction and response from their adult caregivers (Table 3). These interventions are necessary and lifesaving but “painful” and “awful” too. Other descriptive terminology spoke of the “uncomfortable”, “traumatising” and “invasiveness” of the medical and nursing procedures and the resultant “pain”, “stress” and “suffering” endured by the infants. One mother described her son’s experience as a “mission impossible”. These events are aimed at curing and preserving life but this “mission impossible” also represented the despair that can pervade the enormous and costly task of doing this (Table 3). The infants voiced their distress through their physiological responses and through their body language. There were notable abrupt changes in states of consciousness, with repeated disruptions to their sleep. When prompted, the adult caregivers were able to reflect on and acknowledge the “magnitude of the task the infants face”. Repeatedly health care providers when carrying out procedures were observed to mimic behaviours seen in the infants, as if sharing in their distress (Table 3). Staff acknowledged this behaviour but also admitted that they can become “task-focused” or even “disengaged” to complete necessary procedures. One interviewee commented:

“...as I said, the baby is stuck in the middle of it all and sometimes, I suppose, it’s easy to forget that they are actually a person, you know, the baby almost becomes like an object in the bed.”
(NICU nurse 1)

Echoed by the following:

“People would do their jobs but not necessarily talk to him, you know, notice him, as a little person.” (JMS 5).

In addition to the physical challenges that the infants encountered, notable too was their reaction to the pharmacological interventions necessary to sustain life. The infants required many medications during their hospital stay, with resultant discernible changes in their behaviours, with both positive and negative effects. Pain relief is paramount to neonatal care but many of the parents questioned the impact of these medications on the infant’s experience. One mother commented:

“... you know, they told me he is sedated, he doesn’t know anything, he can’t feel anything, but I am not sure I am convinced of that. Even if you are sedated, you are still, sort of, he can still hear, feel, you know. I have a feeling he took some of this in, he has stored it somewhere.”

Other parents spoke of the hardships their infants experienced when withdrawing from these medications and the difficulty in providing comfort to them during these times. One father commented:

“She was coming down off the medication, so she was just like, it was pretty bad, every time she would wake, she was just losing it badly.”

Table 3
“All these hard things”: examples from the data.

Data source	Observing the infant	Primary caregivers	Healthcare providers	Observation reflection
	She is extremely unsettled as the procedure begins. She is agitated and upset. Her arms are contained within her blanket, but she is kicking and arching her back. Her heart rate and breathing rate are elevated, her oxygen saturation levels dropping. The monitors sound their alarm. She changes colour, becoming mottled around her mouth. The body language of the adult caregivers, stiff and tense, mirroring Harriet’s posture as the procedure comes to an end.	“When we first came and saw him, he was just needles and tubes everywhere. He was so new in the world and to have had so much done to do him. It is so intrusive. It is just so awful.” Mother 7 “I definitely think he would have been in a lot of pain. He was very uncomfortable.” Father 6 “He definitely, I think, would have been a bit traumatised, like thinking what the hell is going on? Why are you doing this to me?” Mother 6	“All of these cruel things that we do to them, you know I don’t think much of any of the things we do are comfortable for him.” NICU nurse 7 “They are constantly being intervened on, and there are all sorts of odd things around them, like plastic things pushing on them.” Senior surgical staff 1 “I think it has been a predominantly negative experience. You know she has been uncomfortably intubated; she has been stressed out by extubations that have gone awry and the procedures that come with that. She’s been hungry. She’s probably been in pain or discomfort or something. Just so negative when I stop and think about it.” SMS 2 “He would have been there on his bed, stretched out with people poking and prodding him. Then he had his surgery and was intubated and ventilated for that. I think he would have been in and out of consciousness with not a lot of nice things being done to him. Needing tubes all over the place, needles, drips in, things like that.” NICU nurse 6	After watching attempts to secure intravenous access, I must leave, I cannot watch anymore. As I watch, (all that must happen for her to be medically safe) I see and hear her cries- not from a neonatal medical perspective with a focus on urgent and needed care- but as an observer/ a researcher. I feel (differently) for her tiny body; I see it all; it is a hard experience to endure.

3. An emotional challenge

Described by many, as an “emotional rollercoaster”, through our third theme, we describe the range of emotions experienced by the infants, how they expressed these emotions and the interpretation of this “emotional rollercoaster” made by their adult caregivers (Table 4). We witnessed firsthand activities and encounters that brought happiness and joy to the infants, such as singing, cuddling and story time. In these moments infants were relaxed and engaged with their adult caregivers, sharing eye contact and for those infants who were able vocalisations

Table 4
“An emotional challenge”: examples from the data.

Data source			
Observing the infant	Primary caregivers	Healthcare providers	Observation reflection
As she locked eyes with me, following my face and voice, we could see her eagerness to connect. Her response to the red ball and rattle, showed a similar keenness to explore the world. NBO session Case Study 1 He is upset and crying. His eyes wide, his limbs stiff and extended. Stridulous and tachycardic, he fights for air. The doctor holds him in a semi-prone position, containing him as best she can. ...his mother is now at the bedside. Down on her knees, holding his hands to his chest and humming. Offering him comforting words of reassurance. For a short time, his crying stops. The senior doctor enters and in muffled voices the junior doctor updates her. The senior doctor delicately peels back his blanket to observe his breathing. Breathing difficulties continue. The senior doctor speaks to his mother, her body crumbles, her head down, next to his, both crying now. Observation Session Case study 4 As she is recommenced on breathing support, sadness and disappointment fill the room. Observation Session Case study 3	“It was amazing to see this child come out of theatre and open his eyes. The fear in his eyes was gone. There wasn’t any pain. There wasn’t any struggle. He was finally happy.” Mother 6 “I think there would have been times that he felt very scared.” Mother 7 “They do tell us, that when we aren’t here, he is sort of looking around for us, he gets grizzly and upset. I sometimes wonder is he confused, scared, even. But as soon as we are in here, he is just calm you know. He doesn’t cry too much, settles easier. That makes it even harder to leave but what else can we do?” Father 6	“She has experienced separation and loss because she has been separated from her parents and that’s not normal. I think she has experienced pain and distress. She’s had multiple procedures done, she’s had multiple anaesthetics, so I have no doubt at times she would have felt scared. I think she has probably experienced boredom. She has had good times too, though, she loves being cuddled by her mum, the nurses are kind but must do their job, we are kind but have to do our job, so she has experienced interactions with all of us, nice ones and kind of interpersonal ones, as well as hideous ones.” SMS 3 “I think they are just confused and probably, maybe, I don’t know can you be fearful without understanding what it is? You can be upset, I think. I feel you can understand a negative experience but whether you can be fearful of that, em, sort of what’s the right word: worried, about what might happen next, em a degree of anxiety, I don’t know. But I feel these kids have initially no, very few positives to form a reference and then quite a lot of negatives to rile against... it would be like waking up under water, in the dark, not knowing what way is up,	Watching this infant and these events unfold, I am overcome with emotion; I need to leave. I feel worried that he is experiencing sadness, worry, uncertainty, even fear. He is going through this alone. I feel a different type of worry based on my close observation of his experience. Different to my usual concerns when I am providing medical care as a neonatologist- I worry about whether he might be lonely and there may not be enough experiences for him of being held and comforted. I cannot ever properly know how he is feeling but he, like many other infants in NICU receiving lifesaving but highly technical care, seems to have had a very difficult and hard day.

Table 4 (continued)

Data source			
Observing the infant	Primary caregivers	Healthcare providers	Observation reflection
			which way is down. It’s quite a terrible situation.” Senior surgical staff 1 “I think she has experienced pain and fear. I have also seen her looking worried and anxious.” Allied health professional 2 “...my worry is always that feeling of loss when your family are not there, when actually you are more comfortable when they are there; whether they leave when you are sleeping or whether they leave when you are awake, there is always a feeling of loss.” SMS 3

and smiles. During times of medical stability or progress there was a sense of “calm” within the environment, which was in turn expressed and reflected in regulated behaviours and body language from the infants. Witnessed periods of inquisitiveness, where the infants seemed eager to learn about their surroundings, reminded the observer of the developing child within NICU (Table 4). However, in keeping with the tension of our first themes, within the NICU environment infants also experienced and expressed various significant negative emotions. In response to medical or nursing interventions their physiological instability, facial expressions, body language and vocalisations portrayed their “fear” and “anxiety” (Table 4). With medical complications and evolving diagnoses came much “sadness”. This emotional vulnerability impacted all who bore witness and shared in the infant’s experience, and at times the emotional reflections of the adult caregivers were so intertwined with the infant’s experience it was difficult to separate one person’s experience from the other. One interviewee commented:

“Things have changed since she was re-intubated. She has struggled for so long and now she is so quiet, tired, and her parents seem distant, scared. They are all so stressed. It is hard and sad to watch.” (NICU nurse 3).

Another significant negative emotional challenge, which was discussed in-depth, was the “loneliness” the infants encountered during their NICU admission (Table 4). The infants were often observed to be “alone” at their bedspace, surrounded by “strangers” and “machinery”. This physical isolation evoked much reflection from their adult caregivers. One interviewee commented:

“I think it must be awful to be alone, to be lonely and by yourself in this place.” (NICU nurse 5).

Parents were typically present on the ward from late morning to early evening. One mother commented:

“I think I was quite scared that he was going to feel really abandoned, really alone in there.” (mother 7).

4. Moments of meeting

Our 4th theme represents “moments of meeting” between infants and their adult caregivers. These moments of connection reflect the intimate, human side of NICU, where infants experienced nurturing love and protection despite the complicated technological surroundings (Table 5). Based on observation, infants experienced and responded positively to moments of affectionate human touch by showcasing calm and regulated behaviours. In quiet, alert state they interacted with their adult caregivers, sharing conversation and mutual gaze (Table 5). These moments of connection were found in simple activities; skin-to-skin cuddles, reading, singing, music, bathing, memory making, massage, visits or phone calls from family members. When describing these

Table 5
“Moments of meeting”: examples from the data.

Data source	Primary caregivers	Healthcare providers	Observation reflection
Observing the infant			
As I enter the room Harriet is sleeping, swaddled and contained in her mother's arms, listening to a story her mother is reading. Sometime later she begins to stir. She wakes from a light sleep and the two share a moment of connection and intimacy. Harriet's body is mostly still, her breathing settled, as she gazes up at her mother, holding her finger and sucking vigorously on her dummy. She spits the dummy out and blows bubbles. Her mother affectionately wipes them away. For a short time, it's like a game between them-mother jokingly and playfully saying “are you blowing bubbles at me, cheeky, cheeky”.	“There are moments when he will open his eyes, and he just looks at me. He will just stare at me and his little nose will go up, like a little cringe and then I can see that, that's you and me connecting right now. It's amazing. Just that look in his eye. It feels like he is looking into my soul. He is calm and relaxed, we are together.” Mother 4	“I think she just feels at home with them, and she doesn't feel at home with us. There is a definite difference in her when her family are here, she settles right down. We've even noticed that she does better when a change is made with her medical care when she is being cuddled by her mum or dad. So, we are only going to make changes, if possible, if she is doing that because then she doesn't notice and that must be something to do with what she is experiencing and what she is going through. So, I think she experiences comfort and love when she is with her parents even although there are abnormal things happening to her.” SMS 3 “There have been some beautiful times too, times with her mum and dad, where she has been able to settle and have some really special moments.” Allied health professional 1	In this moment as they sit together sharing fishing stories and holding one another, the NICU environment and the pain from earlier today almost disappears.
Observation Session			
Case study 3	“I got upset today daddy having my clothes taken off, but listening to your voice and feeling your touch, helped me to calm, my breathing settled, my hiccups went away, and my colour went back to normal.”		
NBO session			
Case study 2			

moments, the primary caregivers spoke of the joy they shared with their infant. In general, these “simple things, should be cherished, not rushed, or taken for granted” because this is “when you feel like a parent in here”. During NBO sessions, participants were able to delight in the social responsiveness of the infants. Noticing and acknowledging the infants’ skills and capabilities, highlighting the infant as a developing individual. According to the healthcare providers these experiences, “ones of love and connection”, also have a beneficial influence on infant behaviour, physical health, wellbeing and growth (Table 5). They acknowledged that parents provide a place of safety, acting as a “emotional scaffold” and “protective force” at the bedside and this in turn has a powerful impact, promoting recovery and healing.

4. Discussion

In this innovative research we explored the lived experiences of infants in the NICU environment using data obtained from several sources. Central to our study was the observation, understanding and interpretation of an infant’s behavioural cues. These psychobehavioural tools enabled us to capture the infant’s physical and emotional states and assisted the adults surrounding the infant to reflect on the infant’s experience. Across the 7 case studies, we identified 4 strong patterns or themes in the data, highlighting with raw clarity the unspoken reality of life in neonatal intensive care.

As illustrated in themes one and two, the NICU environment is one of noise, light and bustling activity, where healthcare providers perform the medical/nursing tasks necessary to maintain health and save the lives of ill infants. Infants were often shrouded by their pathology, adhering to an adult agenda, with the primary focus of care being physical health. The infant as a developing person lost, their voice muffled amongst the urgency of critical care. These experiences are not normal for a developing infant and as demonstrated in themes two and three, can result in unintended trauma, leaving an infant feeling scared, confused and lonely. This unintentional hurt is the by-product of what happens within NICU, highlighting the paradoxical nature of neonatal care [29]. The NICU environment and the medical care that saves and preserves life comes at a cost to the infant’s experience of living, potentially setting aside other important physical and emotional interests an infant has, causing inadvertent harm [5,30–32].

This early life stress for infants in NICU is well established in the literature [3,5,30,33–36]. This research adds a fine-grained, real-time exploration of this stress from multiple sources to both identify/bear witness and to assign meaning to the infant’s personal experiences. We move beyond their physiological responses and physical health, applying a holistic filter to their unique NICU experience. We saw firsthand the distress produced because of the NICU environment. The medical care by its very nature causes pain and discomfort, impacting the infant and all who share in their hospital journey. Margaret Cohen, following close observation of infants in NICU, described a triangle, connecting the infants, their parents and the healthcare providers, fraught with difficulty, underpinned by trauma [37]. We similarly observed the interwoven challenges of pain, stress and separation and build on this concept that all individuals within NICU are interconnected by unintended yet stressful experiences. The infants are often in pain and alone. Their anonymity seen and felt. Our data touches on the trauma experienced by parents and healthcare workers. Parents experience harm: past research shows there is loss of identity due to uncertainty in their parenting role and heightened vulnerability to mental health disorders [38–40]. It is traumatic for clinicians to bear witness to all this pain and so clinicians too suffer vicariously [37]. We witnessed some periods of disengagement from the infant as a person to prioritise medical care.

Our research affirms the tension of the infant’s NICU experience but also offers an opportunity for change. We recognise and acknowledge the challenging environment, one that is on many levels antithetical to nurturing a child’s independence and emotional wellbeing, but the

NICU environment also offers hope of life and despite the clinical reality can provide important and heartfelt moments of meeting and connection. In our fourth theme, “moments of meeting”, we saw a glimpse of the human side of NICU. A place where the infant is no longer vulnerable, celebrated for their uniqueness and afforded the opportunity to focus on other important aspects of their development. We saw firsthand the power of relationships and connection, emphasising that compassionate interactions between infants, families and healthcare providers form the foundation for trust, healing and growth [30]. Nadia Bruschweiler-Stern, a developmental paediatrician described the importance of the neonatal moment of meeting to build dialogue in the developing relationship, promoting attachment and strengthening the infant-parent bond [41]. Infants thrive on nurturing interactions. Every touch, every moment of eye contact, and every soothing voice fosters brain development and emotional stability. In NICU, these interactions are essential and provide a basis to inform adjustments to the NICU environment, to strengthen positive moments, reduce stress and diminish the negative impacts of neonatal care [30]. In recognising the infant’s cues and behaviours healthcare providers and parents alike can harness the infant’s strengths and capabilities and invite them to participate in their own care, working with the infants, instead of doing to them.

The importance of parent-infant emotional connections and nurturing human interactions to improve physiological stability and support optimal neuroprotection and emotional development of newborn infants is by no means a new concept in neonatal care. Family-centred developmental care has been practiced and studied since the 1980s, kangaroo care since the 1970s, and bonding and attachment since the 1960s but as we and others have documented implementation is slow and inconsistent; and amidst the urgency of intensive care it can be, at times, hard to achieve [42]. These models all seek to elevate the infant’s experience of neonatal care but do not necessarily derive their conceptual frameworks from direct infant behavioural observation. The different voices (infants/parents/clinicians/observer) in this research provide a comprehensive and holistic approach to understanding the infant experience and we hope serve as the much-needed catalyst for change. By going directly to the infants themselves, strategies for change are derived from the actual experience and communication of the infants and those closest to them. We have shown that infants have a lot to “say” about their experience and their adult caregivers have the skillset to “listen” and reflect on these experiences, if afforded the opportunity to do so. So, with that in mind, we ask, can we partner with the infants in our care and empower their voice? How can our care-giving interactions be led by the knowledge that early experiences matters and that we hold the power and skillset to shift the balance from negative to positive through simple nurturing acts that recognise the infant’s capabilities? By respecting individuality and attuning to infant behaviours, can we change or re-balance some of the care interactions to account more for the infants themselves and not their pathology? Can we empower clinicians to “care” for not only the physical needs of the child but also their psychosocial and emotional wellbeing to allow infants to not only survive but thrive?

4.1. Limitations

This study was designed to explore the early lived experiences of infants hospitalised in NICU. The unit in which the study took place predominantly cares for infants born at term gestational age. We therefore did not capture the perspectives of the preterm infant and their caregivers. We must also acknowledge that our data is subject to, and reliant on, interpretation of experience. Each source having their own strong, emotional lens or filter through which the experience was viewed and described [43,44]. Our role was to present the voice of the participants within its context and make sense of this in relation to the research question and line of enquiry. To address the potential for bias we have ensured the interpretive process is transparent by making

visible, through extensive quotes from participants, our approach to interpretation of results.

5. Conclusion

Early life experiences have a lifetime’s influence, laying the foundations for all aspects of development and functioning; physical, cognitive, emotional and social. By asserting the infant as an active participant in neonatal research, this study aims to give voice to the infants receiving neonatal care, providing a rich and comprehensive account of their hospital experiences and provides a platform for further work in this area. Hospitalisation in the newborn period poses a significant challenge to the developing infant by virtue of the complex and confronting early life experiences they endure, both physically and emotionally. However, amidst the backdrop of NICU there are moments of powerful meeting and connection, that serve to protect and nurture the developing infant. By listening to and respecting the infant’s unique perspective, we place the infant as a person central to their own care and can begin to promote immediate actionable change to better their early life experiences, developing strategies and future areas of research to improve their longer-term health outcomes.

CRediT authorship contribution statement

Natalie Duffy: Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Leah Hickey:** Supervision. **Karli Treyvaud:** Supervision. **Clare Delany:** Supervision.

Contributor statement

Natalie Duffy oversaw all aspects of this project. She developed the idea to investigate the lived experience of infants hospitalised in NICU. Together with Leah Hickey, Karli Treyvaud, and Clare Delany, this research was undertaken. With the guidance of Leah Hickey, Karli Treyvaud, and Clare Delany, Natalie Duffy has gained ethical approval to conduct this study. Natalie Duffy performed all data collection. Natalie Duffy transcribed the interview recordings verbatim. Natalie Duffy in consultation with Leah Hickey, Karli Treyvaud and Clare Delany performed thematic analysis. Natalie Duffy wrote the initial draft of this result manuscript and coordinated with all authors for edits and approval of the final manuscript.

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Declaration of competing interest

None declared.

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