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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

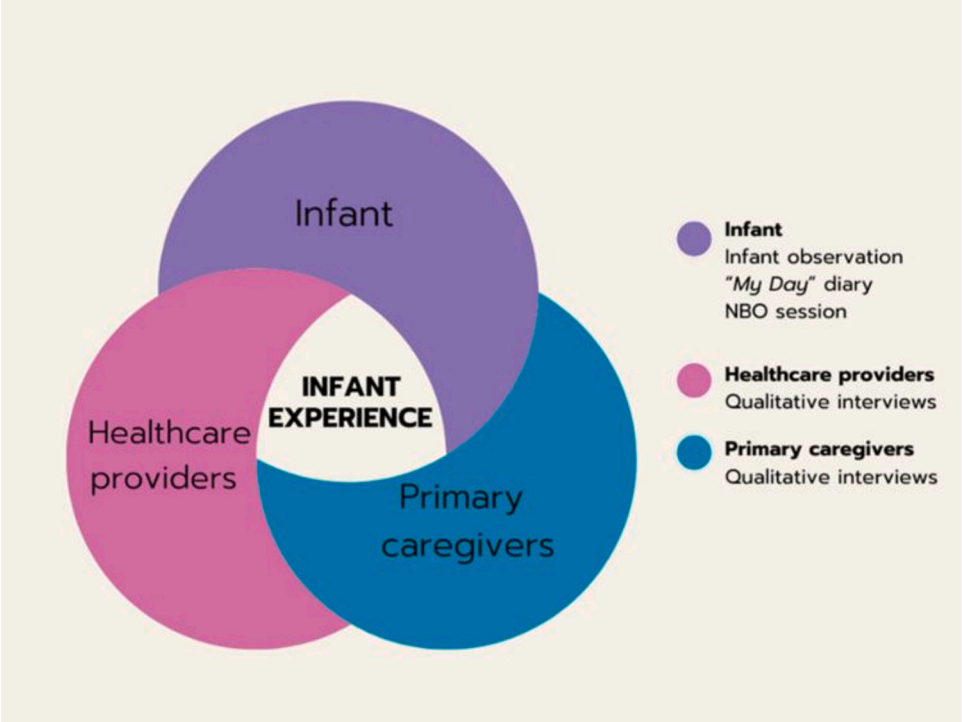

Fig. 1. 360-degree phenomenology and data collection methods.

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 where 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			
Observing the infant	Primary caregivers	Healthcare providers	Observation reflection
Everything is alarming, there are people everywhere, all working to stabilise her. Observation Session Case study 3	*"It is a scary and safe place."* Mother 4	*"It's a flurry of activity in there with lots of interruptions and painful, I suppose for some babies."* JMS 4	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.
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. Observation Session Case study 7	"*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	*"…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	
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. Observation Session Case study 4	"*She's surrounded by lots of beeping, lots of noises, lots of people. A lot going on."* Father 5	*"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	

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. Observation Session Case study 3	"*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, 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	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.

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 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.

Table 5
"Moments of meeting": examples from the data.

Data source			
Observing the infant	Primary caregivers	Healthcare providers	Observation reflection
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*". 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	*"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.

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. Margart 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 closet 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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MINI REVIEW

The newborn behavioural observations system: A relationship-building intervention to support families in the neonatal intensive care unit

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Abstract

Aim: Relationship-based interventions for neonatal intensive care unit families have potential to improve parent and infant outcomes; yet, their implementation has been modest within systems of care for high-risk newborns. The purpose of this paper is to describe a relationship-building intervention, the newborn behavioural observation system, summarise the evidence supporting its use, and address its clinical application for high-risk parent–infant dyads in the neonatal intensive care unit.

Methods: We summarise the extant literature describing the use of the newborn behavioural observation system in high-risk populations.

Results: While the body of literature supporting the use of the newborn behavioural observation system is modest, several randomised controlled studies have highlighted statistically significant and clinically meaningful gains in infant development and parental mental health. In these studies, the intervention was often integrated into existing systems of care and included high-risk parent–infant dyads.

Conclusion: The newborn behavioural observation system is a promising intervention designed to support the early challenges of high-risk infants and their parents. Future research should examine its effects in diverse neonatal intensive care unit populations and professionals, strive for continuity of care from inpatient to post-discharge follow-up and developmental support services, and include more longitudinal studies.

1 | INTRODUCTION

Advances in neonatal intensive care over the past decades have led to dramatic improvements in infant survival and reduction in disability. However, the risks of cognitive impairment and social and emotional challenges among children and young adults born preterm remain high. In addition to the risk of brain injury that accompanies prematurity, primary altered neuronal maturation may also contribute to developmental disability.[1] It is well established that the perinatal period is a sensitive stage during which sensory, social and emotional experiences influence synaptic development and important aspects of subcortical brain architecture.[2] What, then, are the implications for infants and their parents when postnatal life begins in the neonatal intensive care unit (NICU)? Brain development that would typically occur in the intrauterine environment is disrupted and, in the course of receiving lifesaving care, the neonate's

Abbreviations: ANOVA, analysis of variance; BDI-2, Battelle Developmental Inventory, 2nd edition; BSID-III, Bayley Scales of Infant Development-III; CESD, Center for Epidemiologic Studies Depression scale; CGA, corrected gestational age; EAS, Emotional Availability Scales; EI, early intervention; EPDS, Edinburgh postnatal depression scale; GA, gestational age; HVI, Home Visiting Index; IPKS, Index of practitioner knowledge and skills; MANCOVA, multivariate analysis of covariance; NBAS, Neonatal Bbehavioural Assessment Scale; NBO, Newborn behavioural observations system; NDKQ, newborn developmental knowledge questionnaire; NICU, neonatal intensive care unit; NIDCAP, newborn individualised developmental care and assessment program; PASS, perinatal anxiety screening scale; RCT, randomised controlled trial; SCID-5, structured clinical interview for DSM-5.

expected early postnatal experience is dramatically changed. For infants, the moment by moment sensory and interpersonal encounters of the first days and sometimes weeks of life (which is determining brain architecture) is radically different from that of the typical term newborn and marked by multiple caregivers, frequent invasive and painful procedures, and variable contact with their parents. These children, whether due to prematurity, acute illness or congenital anomalies, are likely to experience early diminished self-regulatory capacity compared to healthy term newborns, leading to communication cues that are more difficult to read and greater challenges with social engagement. Parents of babies in the NICU face high levels of stress, mood disorders and anxiety symptoms.[3] They must grieve the loss of a healthy birth experience and often cope with a range of responses including fear, guilt, displacement as parents and lack of confidence in their caregiving capacity. Parental internal distress may in turn interfere with the capacity to engage in sensitive caregiving. In summary, during a critical window of relationship-predicated development, the infant and parent each face challenges in their capacity to engage with one another that may hinder the infant's development, the parent's well-being, and the ongoing quality of the relationship between them.

As neonatal intensive care has evolved, NICUs are striving to become increasingly family-centred, welcoming parents' presence and involvement in their infants' care. In addition, over the past two decades, a myriad of both NICU and post-discharge based interventions have aimed at supporting infant development, parental mental health and the early parent–infant relationship. In general, most such interventions can be roughly categorised under three headings: sensory-based experiences; parent–infant interaction guidance; and infant assessment, intervention and support programmes. In recent reviews, some of these interventions have shown promising effects on maternal traumatic stress, maternal depression, infant weight growth, infant development and mother–infant interactions[4,5]; yet, their implementation has been modest within systems of care for high-risk newborns; that is, babies who are at higher risk for adverse developmental or other health outcomes than the typical newborn, whether due to prematurity, neonatal illness, congenital anomalies or parent risk factors such as substance use disorder or mental illness. There remains no firm consensus for how to best meet the intertwined goals of supporting early development, parent mental health and parent–infant relationships in NICU care.

In a timeline parallel to many of the modern advances in neonatology, T. Berry Brazelton and colleagues recognised the individuality of each newborn and synthesised the understanding of early neurobehavioral functioning in the Neonatal Behavioural Assessment Scale (NBAS).[6] His colleague, Heidelise Als, extended this understanding to the preterm infant in the Assessment of Preterm Infants' Behaviour[7] and the Synactive Theory of Development,[8] leading the development of the Newborn Individualised Developmental Care and Assessment Program (NIDCAP).[9] The purpose of this paper is to describe the Newborn Behavioural Observation System (NBO),[10] an intervention with roots in both the NBAS and the Synactive Theory of Development, aimed at supporting the newborn–parent relationship through shared observation and understanding of the infant's behaviour as communication. Adopting a collaborative, non-didactic stance between professional and parent with a shared curiosity about the emerging personhood of the infant, the NBO offers a unique contribution to family-centred care. We discuss its adaptation to the NICU setting, the small but promising body of evidence supporting its use, and the gaps and challenges in NICU-specific research.

Key notes

- Sensitive caregiving is important for infant development and parental well-being and supports a healthy parent–infant relationship.
- The newborn behavioural observations (NBO) system is a relationship-building intervention focused on understanding infant behaviour as communication to support early parenting.
- Research supporting the NBO as an effective intervention for infant development and parental well-being is promising, albeit modest, though research specific to the NBO in the neonatal intensive care unit is needed.

1.1 | Description of the intervention

The NBO is a brief, flexible intervention designed to help parents understand their baby's competencies, challenges and individuality, to inform caregiving and contribute to the development of a positive parent–infant relationship from the very beginning. Although real-time observations provide valuable information about the baby's functioning in the moment, these observations are emphatically not portrayed as assessments. The NBO is inherently strength based, seeking to understand *who the infant is* rather than *what is wrong with them* and honours the parent's perspective and experience with their child. Through shared, non-judgemental observation, the self-regulatory limitations of the infant are placed into developmental context while parents' knowledge of their child is respected and amplified and moments of connection between parent and infant are underscored and celebrated.

The NBO is described in the TIDieR format in Table 1.

Training in the NBO consists of a 2-day in-person or virtual workshop followed by self-study of the NBO handbook, hands-on practice and mentoring. Curricular content includes practical skills in the administration of the NBO items along with theoretical frameworks to understand and support the contributions and tasks of the *infant*, the *parent* and the *practitioner* during the NBO. For the *infant*, Als' Synactive Theory of Development is the framework used to understand early infant behavioural organisation and state regulation during a time of rapid brain development.[8] For the *parent*, a loose hierarchy of psychic and regulatory tasks is proposed to understand

TABLE 1 TIDieR table for the newborn behavioural observations system.

Brief Name	Newborn Behavioural Observations System (NBO)
Why	Understanding the newborn as a unique individual and their behaviour as communication can guide sensitive caregiving and support early parenting, particularly because NICU-hospitalised families are at risk for: • Adverse developmental outcomes for the baby • Mental health disorders for the parents • Difficulties in the early parent–infant relationship
What (materials)	• NBO 'kit' consisting of a small red ball, penlight and rattle • NBO Recording form • NBO Parent Summary form • NBO Fidelity Checklist Materials are provided as part of in-person or virtual NBO Training workshops delivered by the Brazelton Institute or one of its international affiliates. *Understanding Newborn Behaviour and Early Relationships: The Newborn Behavioural Observations (NBO) System Handbook* is available in paperback and ebook formats through Brookes Publishing (www.brookespublishing.com) and online booksellers.
What (procedures)	*Administration* (*10–30 minutes, depending on the baby's state and fragility and the parent's responses*) The NBO consists of up to 18 structured observations designed to both demonstrate the infant's competence and mildly challenge their self-regulatory capacity. Which items are included is guided by the baby's states (sleep, wake, cry), stress signs and parental responses during the encounter. The primary goal of every NBO is to use the infant's behaviour as communication to guide sensitive caregiving and support the caregiver–infant relationship. The 18 NBO items: Sleep protection to light / Consolability Sleep protection to sound / Response to face and voice Motor tone upper and lower extremities / Response to face Rooting / Orientation to voice Sucking / Orientation to rattle Hand grasp / Visual tracking of red ball Shoulder and neck tone – pull to sit / State regulation Crawling response / Response to stress Crying / Activity level *Documentation* NBO Recording Form (*10 minutes*) 3-point scale for each item and free text areas to summarise strengths and challenges. As an observational tool, not an assessment, the 3-point scale is meant only for descriptive purposes and has not been standardised or validated. NBO Parent Form (*15 minutes*) Documents the NBO for caregivers and consists of a narrative section and an area in which observed behaviours and their meaning in terms of strengths, preferences and challenges are simply described 'in the baby's voice'.
Who provided	Wide array of perinatal practitioners, including physicians, nurses, midwives, psychologists, social workers, allied health professionals, home visitors and doulas. With appropriate mentoring, peer support personnel can also implement the NBO.
How	Face-to-face encounter by a trained practitioner with the infant and at least one caregiver
Where	Any inpatient or outpatient setting, ideally conducted in a quiet, dimly lit room where all present can comfortably gather around the infant. In real world practice, practitioners adapt to the constraints of their work environments.
When and how much	As an observational, relationship-building tool, there is no minimum or maximum number of times the NBO is administered.
Tailoring	• Inherently flexible such that items are chosen or omitted based on the infant's state and tolerance and the caregiver's needs and responses • The self-regulatory capacities observed in the NBO are generally achieved by 3 months CGA, though may be later in fragile infants
Modifications	• Originally designed for term newborns but be adapted for younger or more fragile neonates with careful attention to the infant's capacity for stimulation

what parents may face during this sensitive phase in parent–infant relationship and family functioning. And lastly, to support the *practitioner*'s parallel scaffolding as they enter into relationship with the infant and parent, the NBO training elaborates on practitioners' tasks and the qualities that offer support to both the infant and the parent. Awareness of cultural differences in parenting and the risks of implicit bias are woven through the curriculum.

1.2 | Implementation process

The NBO was originally designed for infants beginning at 37 weeks corrected gestational age (CGA). The typical term newborn will 'outgrow' the NBO by 3 months of age. The NBO is designed to be used flexibly in both inpatient and outpatient settings by a wide array of practitioners, including nurses, physicians, allied health professionals, social workers, psychologists and even peer mentor professionals with appropriate training and mentoring. With only simple equipment required, the intervention is decidedly low-tech and has been implemented across the spectrum of settings from highly resourced intensive care units to rural villages in low-income countries. Parents are encouraged to include whomever they consider to be an important member of their baby's world in NBO sessions.

1.3 | Adaptation and modification

While the NBO was originally developed for full-term infants, many NICU-based practitioners and NBO training faculty have discovered its utility to support parent–infant relationships with preterm and other fragile newborns. To this end, the NBO must be modified with close monitoring of the infant's tolerance of handling and threshold for stimulation. Although the NBO is taught as a stand-alone encounter, many practitioners as well as NBO training faculty report that, in the real world, they leverage the flexibility of the NBO to weave its therapeutic approach and contents into their existing roles with newborns and families. The NBO items are also often integrated into routine care activities as well as during quiet times when parents are holding their baby at the bedside. In the NICU context, particularly given the NBO's foundation in the Synactive Theory of Development, this can create a common language of behaviour observation among various therapists, nurses, physicians, perinatal mental health providers and parents. The NBO also informs providers' clinical impressions about the infant and helps to develop intervention strategies with parents that are individualised to their infant, rather than generic developmental guidance. For example, a physical therapist may use the NBO as part of a developmental session to promote optimal movement patterns, encourage social interaction and facilitate state regulation. The session could occur prior to the infant's routine care and feeding time, allowing therapist to observe with parents how their infant sleeps and wakes (i.e. habituation items); moves, tolerates position change and handling during routine cares (NBO motor items); and interacts when held at the bedside before/after feeding (responsiveness items). Speech therapists and lactation consultants may use the NBO motor, consolability and state regulation aspects to promote oral feeding skills. Regardless of discipline, all providers can use the relationship-building principles and choose specific NBO items to provide individualised, family-centred, 'moment by moment care' that optimally supports parent–infant interaction. Given its nature as an observational tool, the NBO can be repeated over time throughout the developmentally relevant window. While this approach begins in the NICU setting, it can extend to post-NICU services such as infant follow-up, outpatient care and Early Intervention (EI) services.

The use of the NBO in the NICU provides an opportunity to engage with parents and support them in learning their baby's unique developmental skills at a critical time when environmental, emotional, and systemic barriers can negatively impact the emerging parent–infant relationship.

1.4 | Research on effectiveness

The available literature on the NBO has so far demonstrated that it is a versatile tool used by a range of professionals who work in diverse clinical and cultural settings.[11] While the NBO is used clinically in the NICU, its effects have not yet been studied in that setting. It has, however, been examined in early intervention with high-risk infants with past NICU stays.[12–14]

Although there is limited research on the effects of the NBO, a number of studies with rigorous methodologies have recently been published examining a range of outcomes including those for parents, the parent–infant relationship, infant development, and practitioner confidence.[12–16] The following summary focuses on the research that has emerged to date from the most rigorous studies and/or closest to the current population of interest (high-risk infants and their families), as well as those outcomes that address the key challenges we have outlined in our framing of the NBO's rationale, including self-regulatory challenges for high-risk newborns, mental health risks for parents of high-risk newborns, and resultant threats to sensitive caregiving with downstream consequences on infant development.

As summarised in the CONSORT table (Table 2), six published papers on the NBO meet the above criteria.[12–17] Some of those studies were conducted with first time mothers,[15–17] and some in the EI setting.[12–14] All studies provided home-based NBO interventions with three of the studies also including NBO interventions in the hospital setting prior to discharge home.[15–17] The frequency of NBO interventions ranged from two to eight sessions. Outcome measures were varied and included findings on parental mental health such as reduced postpartum depressive symptoms and reduced anxiety[14,16,17] Increased maternal sensitivity to the infant during parent–infant interaction was also noted in two studies.[15,17] In the study with high-risk infants in early intervention, improvements in infant developmental outcome was noted and mothers receiving the NBO intervention had greater

TABLE 2 Table of Randomized Controlled Trials of the NBO following the CONSORT guidelines

	McManus BM, Nugent JK. *J Reproduc and Infant Psychol.* 2011;29(4):395–403	McManus BM, Nugent JK. *J Behav Health Serv Res.* Jul 2014;41(3):381–9	McManus BM, Blanchard Y, Murphy NJ, Nugent JK. *Infant Ment Health J.* Nov 2020;41(6):757–769
Trial Design	RCT	RCT	RCT
Eligibility criteria for participants	EI-eligible infants <6 wks (corrected age), caregiver >18yo who spoke or wrote English or Spanish	EI-eligible infants <6 wks (corrected age), caregiver >18yo who spoke or wrote English or Spanish	EI-eligible infants <6 wks (corrected age), caregiver >18yo who spoke or wrote English, Spanish or French fluently
Settings	Home-based	Home-based	Home-based
Interventions	4–6 weekly home visits (up to 8) from an EI NBO certified provider	4–6 weekly home visits (up to 8) from an EI NBO certified provider	3–4 weekly home visits from an EI NBO certified provider
Outcomes Measures	Index of Practitioner Knowledge and Skills (IPKS) following the final home visit	Home Visiting Index (HVI) following the final home visit	Bayley Scales of Infant Development-III (BSID-III) Adaptive and Social Emotional Scale by phone interview at 3 and 6 months CGA; Battelle Developmental Inventory, 2nd edition (BDI-2) at EI entry and 6-months CGA. Centre for Epidemiologic Studies Depression Scale (CESD) at 3 and 6 months CGA
Sample size	$N = 18$ EI providers (intervention = 9; usual care = 9)	$N = 38$ parents (intervention = 25; usual care = 13)	$N = 38$ (intervention = 16; control = 22)
Statistical methods	Adjusted mixed linear regression models to examine group differences in knowledge and confidence IPKS subscale scores	Adjusted mixed linear regression models to examine group differences in HVI sub-scale scores	Adjusted quantile median regression (due to skewed data) to estimate group differences in the change in each outcome measure between EI entry and 3 months and 6 months
Outcomes and estimation	NBO providers reported greater confidence (mean difference = 2.2, $p < 0.05$) than usual care providers. No difference observed in knowledge subscale scores.	NBO group reported higher quality of care related to facilitating optimal parent–infant social interaction (mean difference = 3.1, $p < 0.05$). No differences were observed for the other sub-scales.	At 6 months: Greater gains in BSID-III Communication ($b = 1$ [0.2, 1.8]), BSID-III Self Care ($b = 2$ [0.1, 3.9]), BDI-2 Perception and Concepts ($b = 2$ [0.4, 3.6]), and BDI-2 Attention and Memory ($b = 3$ [0.4, 6]) scores (i.e., 0.67 effect size); marginally significant higher scores BDI Social Role ($b = 1.5$ [−0.8, 2.9]) and Gross Motor ($b = 2.1$ [−0.6, 4.8]); greater decline in maternal postnatal depressive symptoms ($b = -2.0$ [−3.7, −0.3]).
Harms	None reported	None reported	None reported
Limitations (potential bias, imprecision)	Small sample size and limited follow-up	Small sample size and limited follow-up	Small sample size. No baseline CES-D or BSID; limited (6 months) follow-up
Generalisability	Home-based programming for high-risk infants and their families	Population-based programming for families with high-risk infants	High-risk infants in early intervention and their mothers

improvements in depressive symptoms than the control group.[14] There is also some evidence to suggest that mothers and providers endorse the NBO as being helpful in promoting optimal parent–infant interaction.[12,13]

In synthesising the extant literature evaluating the impact of the utility and effectiveness of the NBO, several key themes emerge. First, multiple doses may matter. More specifically, in the reported studies demonstrating an association of the NBO with better infant and parent outcomes, families received at least two intervention touchpoints.[12–17] While these studies did not explore the mechanism to explain why multiple better outcomes, we offer a couple of hypotheses. First, the primary goal of the NBO is to strengthen the parent–infant relationship and secondly to strengthen the parent–provider relationship. To this end, the NBO reinforces successful parenting strategies that support infant's early neurobehavior and neurodevelopment. More touchpoints with families using this strengths-based approach likely have ripple effects on critical areas of the family's routine including infant feeding, sleeping and self-soothing. Moreover, the NBO's emphasis on bolstering the parent–provider relationship suggests that multiple NBO touchpoints may result in greater trust, openness and engagement in the developmental strategies discussed during the NBO session.

The second main finding of the literature synthesis is that the positive effects of the NBO are observed in the setting of greater risk. That is, studies that included high-risk mothers or high-risk infants showed more clinically meaningful maternal and infant outcomes. Whether due to the fragile infant's cues being more difficult to read, a mental health disorder that interferes with the parent's

Nugent J, Bartlett J, Von Ende A, Valim C. *Infants and Young Children*. 2017; 30:257–268	Nugent J, Bartlett J, Valim C. *Infants and Young Children*. 2014; 27:292–304	Nicolson S, Carron SP, Paul C. *Infant Ment Health J*. May 2022;43(3):455–473
RCT	RCT	RCT
Primiparous low-risk dyad vaginally delivered 36–42 weeks GA, recruited on postpartum unit	Primiparous low-risk dyad vaginally delivered 36–42 weeks GA, recruited on postpartum unit	Primiparous dyad recruited prenatally before 36 weeks; mother with current positive screen for anxiety and/or depression or history past mental illness
Hospital and home-based.	Hospital and home-based	Hospital and home-based
One NBO on postpartum unit within 2 days of birth and one home visit NBO at 1 month of life	One NBO session on postpartum unit within 2 days of birth and one home visit NBO at 1 month of life	Three NBOs, 1 in first week of life in hospital or at home, and two sessions at age 2 and 4 weeks at home
CARE-Index- (Sensitivity in parent–infant interaction) at 4 months of age	Edinburgh Postnatal Depression Scale (EPDS) at one-month postpartum visit	Emotional Availability Scales (EAS) 4th Edition, BSID-III, and Structured Clinical Interview for DSM-5 (SCID-5) at age 4 months (endline) Newborn Developmental Knowledge Questionnaire (NDKQ) prenatally at 36 weeks, and endline; EPDS Perinatal Anxiety Screening Scale (PASS) at prenatal baseline and endline
$N = 35$ (intervention = 18; control = 17)	$N = 112$ (intervention = 57; control = 55.	$N = 74$ (intervention = 40; control = 34)
Multiple logistic regression analysis with regard to the binary outcome variables, sensitivity in mothers, and cooperativeness in infants, hospital and maternal age	Fisher's exact test for proportion of mothers with EPDS >12 Multiple logistic regression, adjusting for hospital, infant gender and mother's education	Linear mixed models to analyse group differences in depression and anxiety symptoms; MANCOVA to examine between-group differences in EAS; ANOVA to examine between group differences on endpoint psychosocial and infant development measures; Effect sizes expressed as Cohen's d (CI = 95%)
Adjusted OR favoured NBO group for: 'sensitive mother' index 4.95, $p = 0.068$, infant cooperativeness 6.56, $p = 0.035$	NBO was associated with lower levels of depression scores ($p = 0.05$), NBO was associated with a reduction in the risk of major depression by over 75% during the first month after birth.	At 4 months: Positive effect on EAS ($p = 0.049$), and maternal knowledge of infant development ($p = 0.03$); no significant differences in endpoint distress characteristics; NBO group with significant reduction in anxiety symptoms over time $p = 0.014$) and a significant decrease in depression symptoms ($p = 0.006$)
None reported	None reported	None reported
Small sample size and limited (4 months) follow-up	Small sample size and no baseline EPDS	PASS requires further validation; Concern about the validity of reporting individual EAS scales
Mothers at risk for postpartum depression.	Mothers at risk for postpartum depression	Mothers at risk for perinatal depression and/or anxiety

capacity to engage in sensitive caregiving, or a comorbid combination of both conditions, the high-risk dyad faces greater potential for misattunement. Accordingly, with greater risk may come greater opportunity for the NBO to meaningfully improve the parent–infant relationship with attendant positive parental and infant outcomes.

Finally, implementation appears to be important. Specifically, studies that embed the NBO in real world clinical settings provide the most realistic pathways for translation of research findings into improved standard of care practice. For example, one study embedded the NBO into Early Intervention, with NBO training provided to EI providers.[14] Additionally, the study leveraged existing program infrastructure to align with eligibility, service delivery and outcome measure data collection processes to streamline the study procedures to maximise efficiency, reproducibility and sustainability after the study period.

2 | DISCUSSION

Based on the current research, the NBO shows promise for supporting high-risk infants and parents within existing systems of care. Future research should include larger sample sizes with longer follow-up to better understand at-risk children's developmental trajectory over time. Outcomes research with the NBO should continue to target parental mental health and should specifically include non-birthing parents as well as the extended family system. Given that

the vast majority of preterm infants are born in low- and middle-income countries (LMICs) and that the NBO is a low-tech intervention that has a track record of integration into wide array of care models, more research on its effectiveness in LMICs should be prioritised, with recognition of the importance of culturally congruent outcome measures.

While there is a pressing need to better understand the role of the NBO in the NICU setting, this research will face several challenges. Questions include how often the NBO is administered and by whom – therapy staff, bedside nurses, mental health clinicians, or all of the above? Measuring fidelity in NBO delivery is not straightforward, perhaps even more so in the NICU setting where many modifications of NBO items are needed. The NBO fidelity checklist developed in one recent study[17] emphasises the practitioner's interactional skills and practices that we believe are central to the intervention rather than focusing on which or how many NBO items are administered. Finally, challenges for the NICU parent–infant dyad do not end at hospital discharge. Study designs that include both inpatient and post-discharge components are likely to be best positioned for success. To this end, the authors have a research protocol in development that involves providing NBO intervention beginning in the NICU and spanning the first 3 months post term in community-based care. The flexibility of the NBO, focus on providing individualised care, and emphasis on supporting the parent–infant interaction create a unique opportunity to examine its effectiveness in a variety of clinical settings. These NBO attributes also present challenges for researchers related to variability in the NICU population, differences in dose and content of NBO sessions and disparate access to post-NICU services. Yet, contemporary research frameworks such as dissemination and implementation science offer strategies to leverage this variability to understand best practices to optimally support parent–infant relationships.

While NICUs must choose from among a multitude of development- and family-support interventions to benefit their patients, the NBO has unique qualities that deepen family-centred care. Beyond dyadic, the NBO has evolved over time to be truly triadic, including frameworks not only for understanding the infant's contribution to caregiving relationships but also for considering the parent's tasks in engaging with their infant and the practitioner's role in scaffolding the infant-parent relationship. Rooted in Brazelton's appreciation of the unique personhood of the newborn and in Als' Synactive Theory of Development, and fundamentally incorporating the authority of the parent's understanding of their own baby, the NBO may foster a common language and stance across many professional disciplines in the NICU. The resulting experience of repeated positive regard and respect from the care team for the infant, for the parents, and for the paramount importance of their relationship may characterise an ideal therapeutic environment of not only a neonatal but also a *parenting* intensive care unit.

The perinatal period represents a critical developmental window of experience-mediated brain development. By extension, an intervention such as the NBO which targets the quality of the parent–infant relationship in the perinatal period may have outsized potential impact given its timing during this critical developmental window. These considerations underscore the importance of developmental support services which begin in the NICU and then bridge to post-discharge care, including EI and NICU follow-up care.

3 | CONCLUSIONS

Advances in neonatal intensive care have moved the goal in caring for ill and preterm neonates from surviving to thriving. Best practice models for optimisation of developmental outcomes are undoubtedly multipronged, based in the Synactive Theory of Development, attentive to sensory experience, and focused on the critical role of the infant's primary caregivers, both during the inpatient birth hospitalisation and ongoing post-discharge developmental support. Alleviation of parental mental distress as integral to NICU care reaps benefits for the parent, the infant and the health of the dyadic relationships. Finally, comprehensive care of the NICU patient also includes addressing social determinants of health that interfere with a NICU parent's ability to participate in their infant's care. In this sensitive developmental window, every moment matters so that even temporary supports may yield foundational benefit.

The NBO is by no means a silver bullet in the quest to improve developmental outcomes for children who begin their extrauterine lives in the NICU. Indeed, there are likely no such silver bullets. However, given accumulating evidence of its effectiveness in supporting parental mental health, infant development and the quality of primary caregiving relationships combined with its strength-based, low-tech and flexible nature, the NBO deserves consideration for incorporation into NICU and post-NICU care for high-risk infants and families. Accompanying research to refine our understanding of how best to implement this tool will better delineate the NBO's place in the armamentarium of care for our youngest and most fragile world citizens and their families.

AUTHOR CONTRIBUTIONS

Lise C. Johnson: Conceptualization; writing – review and editing; writing – original draft. **Beth McManus:** Conceptualization; methodology; writing – review and editing; writing – original draft. **Yvette Blanchard:** Writing – original draft; writing – review and editing. **J. Kevin Nugent:** Writing – review and editing.

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CONFLICT OF INTEREST STATEMENT

Drs Johnson, Blanchard and Nugent are co-developers of the NBO and co-authors of *Understanding newborn behaviour and early relationships: The Newborn Behavioural Observations (NBO) system handbook*.

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