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360-degree phenomenology: A qualitative approach to exploring the infant experience of hospitalisation in neonatal intensive care

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ABSTRACT

This paper describes the development and justification of a qualitative methodology aimed at exploring the infant's personal experience of hospitalisation in the neonatal intensive care unit (NICU). We begin by briefly reviewing existing methods for documenting and recording infant experiences. These methods focus on the clinical needs of the infant predominantly through quantifiable medical outcome data. Research understanding their experience of receiving clinical care is lacking. By exploring newborn infant behaviour, cues, and communication strategies we assert the infant as a capable participant in neonatal research. We then describe the methodology and methods which we have named 360-degree phenomenology that draws directly from the capabilities and knowledge of the infants themselves. We propose this methodology will address the gap in the literature by enabling a rich and comprehensive overview of the early life experiences of infants hospitalised in NICU.

1. Introduction

An experience can be described as "something that happens to you that affects how you feel" [1].

The research paradigm of phenomenology originated from the works of German philosopher, Edmund Husserl (1913) but it was Alfred Schutz, a colleague of Husserl, who was instrumental in introducing phenomenology into scientific research (1972) [2]. Phenomenology focuses on the study of an individual's lived experience. Lived experience, as it is explored and understood in qualitative research is a representation and understanding of how a person encounters and interacts with the world around them [2]. It privileges the experience of the person who is undergoing an event, valuing the insights and learnings that only that person can offer. The goal of phenomenology is to describe the meaning of these experiences-both in terms of *what* was experienced and *how* it was experienced [3].

The neonatal intensive care unit (NICU) provides care for premature and critically ill infants. Progressive advancements in both perinatal and neonatal intensive care have led to dramatic improvements in the survival of premature infants and those with congenital anomalies. However, despite improved survival rates, poorer neurodevelopmental outcomes persist amongst infants hospitalised in the newborn period [4–9].

Early childhood is the most critical and vulnerable time in any child's development. It is a time when the cumulative effects of both positive and negative experiences on brain growth are remarkably profound, shaping future health outcomes [10,11]. Research has demonstrated that whilst the skills, knowledge and actions of neonatal staff coupled with sophisticated medical technologies are capable of providing extraordinary lifesaving measures, the unique NICU environment and the infant's experience of hospitalisation may be disruptive to several key aspects of early development, such as cognitive impairment and social and emotional challenges in later childhood [6,12,13]. Much of this current literature is focused on quantitative accounts of "*life in*

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NICU". These measurable outcomes act as a proxy for the experience as it might be felt, interpreted, and processed by an infant, resulting in a lack of understanding of the infant's personal perspective of their experience [14].

Other studies in the NICU context have focused on parents and infants' experiences. Parents of hospitalised infants experience high levels of distress, symptoms of depression and anxiety, sleep disturbance and fatigue as they journey with their infants through NICU [15]. Research suggests that hospitalised infants spend 80 % of their time alone in NICU [16]. Specifically, for an average 19 h a day, the infant's primary developmental environment is provided by non-human technology (i.e., incubator, monitor wires, ventilation devices) with the remaining hours consumed mostly with clinical interactions [16]. Clinicians describe the infant's experience as unpredictable, overstimulating, painful, and stressful [17]. A systemic review of painful procedures, for example, indicates newborn infants are exposed to 7–17 painful procedures a day, over the first two weeks of their hospital admission [18]. However, there is very little reference to how the infants cope with these procedures, what they may feel and how they communicate these emotions to their caregivers.

Given the body of evidence linking the importance of early life experiences and future health outcomes there is increasing interest in the lived experience of infants hospitalised in NICU. A sustained focus on the experience of the infants as told by the infant themselves is essential. This gap in understanding the infant's experience through the eyes and communication of the infant themself is increasingly being recognised as a significant omission in the field of neonatal care. One may even argue that there is an ethical imperative to obtain the voice and experience of the infant undergoing neonatal care to complement and better inform research about clinical pathology as well as hospital policies and guidelines, which rely heavily on consumer engagement. Opening a window into their emotional and relational health through a qualitative lens will add an increased understanding of the subjective experience of infants hospitalised in NICU and give greater descriptive meaning to the quantitative data already published. The infant's lived experience, explored in this way, is a missing piece in neonatal research that compliments patient-focused, family-centered care; highlighting that hospitalised infants are individuals with their own capabilities, vulnerabilities, and needs, beyond their physiological pathology, providing future focus for strategies to improve their early life experiences, to better their long-term health outcomes.

2. Understanding newborn infant behaviour

Attempts to systematically observe and record infant behaviour can be traced to the 1950s and were primarily clinician-led for use in clinical and health settings. Peter Wolff made a foundational contribution to our understanding and appreciation of the complexity and competencies of the human newborn. In 1959 he identified that newborns have six behavioural states and infant behaviour has an organised structure. It was his observation of newborn behavioural states that laid the groundwork for Berry Brazelton's work in developing the Neonatal Behavioural Assessment Scale (NBAS, 1973), and Heinz Prechtl's efforts to develop a standardised neurological examination for neonates (1977). Dr. Brazelton contributed an entirely new understanding of newborn infants—their behaviour, their temperament, and their interactions with family and other caregivers. He moved away from the traditional pathology-based approach and instead focused on the strengths of the individual infant. A colleague of Brazelton's, Dr. Heidelese Als expanded this work, focusing her attention to the behavioural repertoire of premature infants. Observing these infants for hours at a time she found patterns and meaning to their behaviour and responses to environmental stimuli. She developed the conceptual Synactive Theory as a framework for understanding human, and especially young infant, behaviour and in 1982 co-authored the Assessment of Preterm Infant Behaviour (APIB), a comprehensive neurobehavioral assessment [19]. In 1984 she introduced the first comprehensive neonatal model of care, the Newborn Individualised Developmental Care and Assessment Program (NIDCAP) into NICU.

After decades of work with the NBAS and NIDCAP both clinically and in research, Dr. Kevin Nugent and colleagues, in 2007, published the Newborn Behavioural Observations (NBO) system [20]. The NBO is an infant-focused, family-centred relationship-based tool, designed to highlight the full richness of a newborn infant's behavioural repertoire and communication style and unlike the other tools relies on direct parental involvement with the infant guiding the interaction [20]. The NBO consists of 18 neurobehavioral observations and is designed for use from birth through the third month of life. These items showcase that newborn infants possess a wide range of visual, auditory, and perceptual abilities that allow them to explore the world around them and to engage in face-to-face, eye-to-eye mutual exchange with caregivers [21]. The infant's behaviour is at the centre of the NBO with the focus on the infant's individuality. Through observation and interaction, the NBO allows infants to fully show who they are: their preferences, capacities, and vulnerabilities. In other words, the NBO provides the infant with a "*voice*" and the infant as a developing person is revealed [21].

The NBO although a powerful tool, will not capture the infant's complete experience of hospitalisation. To fully understand the complexities these infants must endure during their hospital stay there is a need for new methods of research in NICU.

2.1. Using 360-degree phenomenology in NICU to understand the infant's lived experience

Over the last 70 years we have learned much about the behavioural repertoire and capabilities of the newborn infant. Clinicians and researchers alike have used a variety of methods and observational tools to demonstrate that infants are born with a sense of self, and a sense of others, and possess inherent capacities for engagement, reciprocity, exploration, and discovery [22]. Their preverbal stage of development is no longer considered a barrier to including infants in research about matters which directly concern them. Placing the infant at the centre of our research allows those experiencing neonatal care to have their subjective opinion explored, guaranteeing space is made to see, hear, and consider the viewpoint of the infant [23]. Bringing an infant-led approach to research requires placing the infant at the forefront of the researcher's mind and practice. It is about truly being present in observing the infant, providing space to "*imagine*" and reflect on what it might feel like and be like for the infant in the moment [23].

To accomplish our aim of providing an infant-centred, rich understanding, and comprehensive analysis of the NICU experience through the eyes and communication of the infants themselves we devised a particular combination of methods underpinned by the research paradigm of phenomenology. For the purposes of this project, the lived experience, defined in phenomenological terms, is the infant's situated, immediate activities and everyday first-hand encounters within the NICU environment [24].

We drew also from case study methodology and utilised a variety of methods to explore the lived experience of infants in NICU [25]. As depicted in Fig. 1, the "*infant experience*" is our central focus, with each infant forming their own individual case study, respecting each infant's individuality and unique perspective. We began with infant involvement and infant data collection, drawing on what the infants themselves communicate, observing their hospital journey, and then interviews with the significant caregivers adds another perspective of the infant's lived experience. This 360-degree approach allowed us to utilise every possible lens to gain insight into what the infant is experiencing; infant, parent, care-team, and researcher. Methodological triangulation also increases 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) [25–29].

Data collection methods comprised recording the infant's daily

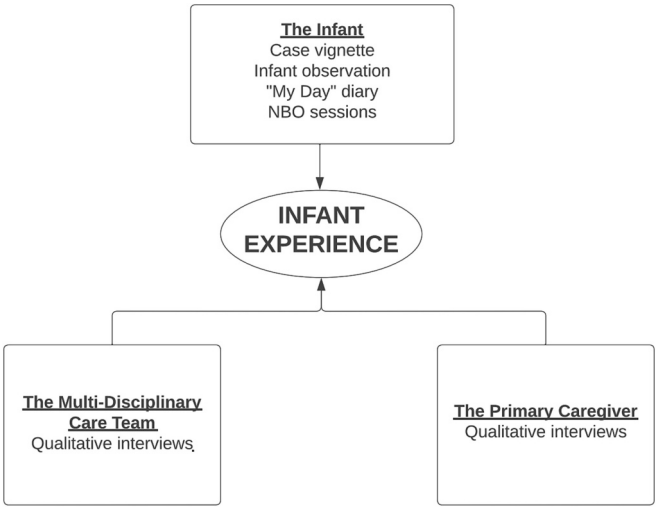

Fig. 1. Illustrates a visual representation of the data collection strategy.

encounters, activities, and opportunities for developing connections and relationships with others with a particular focus on how an infant communicates what they are experiencing and how those caring for the infant interpret the infant experience. The infant's lived experience, explored in this way, allows the infant to become an active agent in neonatal research, with their own "*voice*" and story to tell, and the process of data collection is modelling (and based on) a fundamental orientation to the infant's interpretation and response to stimuli.

This exploratory 360-degree phenomenology approach facilitates a closer, more granular perspective of an infant's experience in NICU, addressing the gap in the literature about how to know about and better understand what a NICU patient experiences.

3. Setting and participants

The research project has been granted ethical approval and is being conducted on a quaternary neonatal unit with 35 beds and approximately 800 admissions per year, caring for infants with complex medical and surgical conditions. Most infants cared for on this unit are born at or near-term gestation ($\geq$ 37 weeks gestation) with an average length of stay being 18 days, however infants with complex pathology can spend months in NICU. For feasibility inclusion criteria included term infants with an expected minimum length of hospital admission of >7 days. Exclusion criteria included diagnosis of congenital heart disease requiring surgery in the neonatal period (these infants are co-managed between two hospital units) or infants being cared for on a palliative care pathway.

Infants are enrolled following written, informed consent by their parents. For each infant key members of their clinical team are also approached to participant in private interviews. Infants participate for their entire hospital admission or for a maximum of 12 weeks.

4. Data collection methods

There are multiple data collection methods as shown in Fig. 1 and described in detail below. As mentioned, we are focused on term infants, but the following methods could be adopted to better understand the experience of preterm infants in NICU.

4.1. Case vignette

The infant's health record sets the scene for their hospital admission. A timeline of the key events taking place during the infant's hospital journey based on data from the health record is documented.

4.2. Infant observation

Utilising infant observation at the bedside we build a complete and empathic understanding of an infant's collective real time experience of everyday life in NICU. The goal of the observation being to describe, in concrete terms, the infant's environment and their behaviours whilst cataloguing their daily activities, interactions, and relationships. The observer, whilst immersed in the complex NICU environment simultaneously reflects on the events unfolding in front of them, "*imagining*" what it may be like to experience these things from the infant's perspective. These observation sessions are informed by the Tavistock Model of Infant Observation developed by Esther Bick [30]. This method of collecting data involves a disciplined process whereby the observer unobtrusively but keenly watches the interactions of the infant within their caregiving world and immediately post session writes up meticulous notes on what was seen from the beginning to the end of the observation session [31].

4.3. "My day" diary

A bedside dairy is used to capture a "*day in the life of an infant in NICU*" during times when infant observation is not possible. The diary details time spent with family, such as skin-to-skin care and medical and/or nursing caregiving interactions over a 24-h period. Any pain scores which are recorded as part of routine NICU care are also recorded. For ease of completion the diary includes a predetermined list of common NICU activities and encounters e.g. blood taking, medical examination, nappy change, as well as space for free text for both staff and families to add further detail. Any person interacting with the infant is encouraged to contribute to the bedside diary.

4.4. NBO session

The NBO permits direct interaction between the researcher, the infant, and their caregiver at the bedside, allowing the infant to showcase their individuality, strengths, and areas that may require support (Figs. 2 and 3 illustrate snapshots from a NBO session with an infant in NICU). These sessions allow the researcher to explore, fine tune and add greater meaning to behaviours that have already been observed at the 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 (indices of the infant's threshold for stimulation); and visual, auditory, and social-interactive capacities (degree of alertness and response to both human and non-human stimuli) [20]. The researcher and parents work together during these sessions to fully understand the infant in front of them.

4.5. Qualitative interviews

Using qualitative interviews, we explore how the adults surrounding the infant describe, account for, justify and rationalise the infant's hospital experience. Parents or primary caregivers are interviewed at two different time points in the infant's hospital journey. Members of the multidisciplinary care team are invited to attend one private interview. The interviews explore not only the physical environment and its impact on the developing infant but the activities and encounters the infants are exposed to. There is a particular focus on the infant's developing relationships. Using a semi-structured interview guide, the researcher sensitively explores the interviewee's ability to reflect and mentalise on the infant experience, as if in the infant's "*shoes*". Interviews are recorded, and then transcribed verbatim for data analysis.

5. Data analysis

Data will be analysed using inductive content analysis (ICA). ICA is a

Fig. 2. NBO session demonstrating the infant's responsiveness. Picture 1 demonstrates response to face and voice. He can engage in mutual eye-to-eye exchange with the NBO clinician. He can track both face and voice. Picture 2 demonstrates visual tracking with a red ball. These interactions highlight a growing awareness of the environment and the capacity to respond and engage in social interaction.

Fig. 3. NBO session demonstrating the infant's organisation of state and ability to cope with stress. Picture 1 demonstrates the infant's ability to habituate to light and protect sleep. In picture 2, we see that the infant was disturbed by sound; awakening from sleep. The infant has pursed lips and a facial frown/grimace. He also developed hiccups. The NBO clinician holds him in a containment hold, bringing his arms to his chest, to help him to return to a regulated, stress-free state.

method of qualitative data analysis well-suited for use in health-related research that has direct relevance for practice and policy [32]. As stated, each infant will form their own case study. Data analysis will occur in two phases, firstly a detailed account of each case will be developed; this is known as in-case analysis. Secondly, analysis across all cases is carried out, referred to as a "cross-case analysis" [33].

5.1. Phase 1

Data will be analysed using the principles of Vears and Gillam's ICA [32]. ICA is an *inductive process* and involves *iterative coding* meaning that the codes used to label the data are developed during the process of coding, based on the actual content of the data set [32]. The codes are identified by the researcher within the data itself. Iterative coding means that the process of coding is not done only once for each document/transcript but is refined based on comparison between documents/transcripts and then repeated. Each document/transcript is coded several times in more refined iterations each time [32].

As described by Vears and Gillam, analysis will take place in five phases, beginning with familiarisation with the data, and then initially coding the data into basic stand-alone segments of text relevant to the phenomenon under study [32]. Content will then be identified, reviewed, and refined. Lastly synthesise and interpretation allows connecting the categories to create a narrative for the reader that gives an overall explanation of the phenomena under study [32].

5.2. Phase 2

Comparing data between cases will be an integral part of data analysis to draw conclusions about the infant's lived experience in NICU.

Data will be managed in NVivo software and presented using visual schema and content categories exemplified with quotations. Quotations will never be presented with identifiable participant information.

6. Conclusion

Early life experiences have a lifetime's influence, laying the foundations for all aspects of development and functioning: physical, social, emotional, and cognitive. Hospitalisation in the newborn period poses a significant challenge to the developing infant by virtue of the varied experiences they encounter.

Despite a notable focus on the importance of early life experiences, research has omitted to include the perspective of the infants undergoing neonatal care. Infants are born with an armoury of behavioural cues and communication strategies to engage with the world around them. Drawing on this skillset we propose a novel, infant-focused methodology, which we have named 360-degree phenomenology to better understand, from the infants themselves their early life experiences in hospital, permitting them a voice in matters that directly relate to them.

Such a focused exploration of the infant experience may uncover gaps in models of care or areas for improvement in the way neonatal care can be delivered to improve the early lived experiences of hospitalised infants. We hope the findings will then lay the foundation for future research, which ultimately strives to improve long-term health outcomes for this vulnerable patient group.

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Natalie Duffy: Writing – review & editing, Writing – original draft, Resources, Project administration, Methodology, Conceptualization. **Leah Hickey:** Supervision, Writing – review & editing. **Karli Treyvaud:** Supervision, Writing – review & editing. **Clare Delany:** Supervision, Writing – review & editing.

Declaration of competing interest

None declared.

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