Imperial College London

Department of Brain Sciences

Lived Experience of Newborn Death:

A Hermeneutic Phenomenology Study

Stuti Pant

2024

Supervisors: Professor Sudhin Thayyil Professor (Dame) Tina Lavender Professor Michael P Kelly

Thesis submitted towards the degree of

Doctor of Philosophy

Imperial College London

ABSTRACT

With technological advances in neonatal intensive care, most deaths occur following withdrawal of life-sustaining treatment. However, little is understood about experiences of those that these deaths effect, including bereaved parents and neonatal intensive care unit (NICU) staff. Thus, I explored the lived experiences of these groups to generate a comprehensive understanding of the phenomenon of newborn death.

A meta-synthesis of existing global qualitative research related to parental experiences of newborn death in a NICU was conducted, including 20 studies from 11 countries (740 participants). The central theme highlighted that an absence of relational care impacts parental grief and bereavement experience. A dearth of published literature and knowledge gap around the holistic lived experiences of parents relating to newborn was evident.

The theoretical basis for the empirical study was hermeneutic phenomenology, guided by the works of Heidegger and Van Manen, exploring essence, and meaning of the lived experience of newborn death. Main data collection method was semi-structured in-depth interviews.

Thirteen parents (9 mothers and 4 fathers) were interviewed. Parental narratives generated a core theme of ‘loss of agency’ that affected their bereavement journey and pushed their grief towards disenfranchisement. Eight NICU staff (5 nurses and 3 doctors) were also interviewed. Analysis revealed an emerging theme, ‘creating an optimal experience for parents’. The overarching phenomenon of the thesis is that, despite the efforts from staff to create an optimal experience for parents, an absence of relational care in the NICU contributed to a loss of agency for parents.

The study provides a new perspective on the NICU lifeworld experienced by parents and staff while living through newborn death, highlighting the misunderstandings and practice gaps. It provides key recommendations with direct implications for research and practice, which should guide efforts in development of pragmatic supportive programmes for grieving parents and training for staff.

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DECLARATIONS

Declaration of Originality

I hereby declare that the work presented in this thesis is my own work, unless otherwise acknowledged and appropriately referenced.

Copyright Declarations

AUTHOR CONTRIBUTIONS

As the primary author of this thesis, I have led all stages of the work presented in this study and am the sole author of drafting the content of this thesis. My supervisors have guided me through every stage of the project. I would like to acknowledge the contribution made by the following people in conducting the metasynthesis of qualitative literature (presented in Chapter 3); Dr Nikolaos Efstathiou (University of Birmingham) who was a collaborator in my NIHR Pre-doctoral fellowship and guided the development of search strategy; Ms Pallavi Muraleedharan (Imperial College London), who independently searched the literature following the strategy outlined in a predefined protocol as well as conducted an independent appraisal of included studies using Critical Appraisal Skills Programme checklist; and Ms Maaheshi Deepika Herath (Liverpool School of Tropical Medicine) who independently generated descriptive themes for metasynthesis.

ACKNOWLEDGEMENTS

This study has been an enriching experience for me. I will take this opportunity to reflect and express my gratitude to everyone who has been there with me on this journey.

For as long as I can remember, it has been my dream to pursue a PhD, and now that I am at this juncture, I cannot help but feel immense gratitude towards all the parents who came forward and shared their stories with me. This study would not have been possible if you did not believe in it. I also want to thank the incredible team of nurses and doctors who participated in the study and supported the recruitment of parents. Your contributions have added richness to the entire narrative.

I would like to thank the Stillbirths and Neonatal Deaths Society (SANDS) for collaborating in this important study and supporting the recruitment process.

I have had the best team of supervisors, who not only guided me at every step of the way in this study, but also imparted many valuable life lessons. I am eternally grateful for your support.

To my friends at work and home, thank you for being there when I needed you.

To my family, my parents and my sister, who are my biggest support system and my loudest cheerleaders. Thank you for believing in me, especially when I doubted myself.

To my husband, thank you for sharing this dream with me, supporting me at every step of the way, and being my anchor. I would be lost without you.

And finally, to my daughter, who was born during this study: Thank you for adding the joy and perspective I needed for this PhD study. I dedicate this to you.

GLOSSARY

Being-in-the-world – German- Dasein, – For Heidegger Being is a 'universal' concept. It is not an entity but an ontological analytic. It enquires into the nature and meaning of the phenomenon of interest. In *Hermeneutic Phenomenology*, Being is a fundamental term of human science research process itself. Heidegger's phrase Being-in-the-world refers to the way human beings (Being) exist in the world or are involved in the world.

Disenfranchised grief – A concept defined by Kenneth Doka in 1989, Disenfranchised grief pertains to a conflict or misalignment between a bereaved individual's sense of entitlement to grieve and denial of the opportunity to do so or the right to grieve.

Epistemology – Study of nature of knowledge. It is a branch of philosophy concerning theories of knowledge. Epistemology is how researchers understand the world. It is questioning and understanding how we know what we know.

Essence – True being of something or the inner essential nature of a thing.

Hermeneutics – The branch of knowledge that deals with interpretation, the theory and practice of interpretation. Hermeneutics is an essential element behind this study.

Life-sustaining treatment – A treatment that is needed to prolong one's life.

Lifeworld – The world as "already there" (Husserl) and modes of being or ways of being-in-the-world (Heidegger). Lifeworld is the world experienced in the subjectivity of everyday life, as sharply distinguished by the "objective" world of positivists. It includes the individual, social, perceptual, and practical experiences.

Lived experience – German- Erlebnis, means "living through something". It equates with living through an experience that is pre-reflective or pre-predicative. Phenomenology attempts to recover the lived meaning of this moment without objectifying these meanings and without turning them into positivistic concepts, or abstract theories.

Ontology – The study of being. It concerns with the nature of social reality, our views about what constitutes the social world and how as a researcher we study it. The ontological assumptions are the researchers' views about the nature of reality that are subjective and is concerned with what it means to *be.*

Paradigm – It is a view, belief, school of thought that a researcher follows, that guides the research methodology, design, and methods to acquire knowledge.

Purposive sample – A method of sampling where participants are drawn from a population known to have experienced the phenomenon of interest (for this study, experience of newborn death).

CHAPTER ONE- INTRODUCTION TO THE THESIS AND RESEARCH

1.0 INTRODUCTION TO THE THESIS

This thesis presents a phenomenological study exploring the lived experiences of newborn death. The purpose of this thesis is to understand the phenomenon of newborn death through the lived experience of parents and neonatal intensive care staff. Specifically, the research explored the essence of parent's journey through their pregnancy and newborn's birth, to the admission in the Neonatal Intensive Care Unit (NICU), with a life-threatening illness, specialist tests, treatments, uncertainties, decision-making and, death of the baby following withdrawal of life-sustaining treatment (LST). Narratives of the lived experiences of NICU staff were sought to gain a comprehensive understanding of the phenomenon. By interviewing participants who had undergone this experience, an in-depth exploration of the phenomenon, using a hermeneutic phenomenological approach was undertaken.

My interest in the issue arose from my experiences as a non-participant observer in the Imperial National Health Service (NHS) Trust's Neonatal Clinical Ethics Committee. Although an agreement of confidentiality limits the details of my observations from being shared, the discussions were often related to disagreements between parents and medical teams on re-direction of care from the baby and value/belief systems. In parallel, I conducted a pilot study to explore the opinion and issues concerning withdrawal and withholding of LST from newborns in different countries including, Italy, Japan, Brazil, Sri Lanka and understood the uniqueness of the UK in ethically permitting withdrawal of LST and therefore, portraying unique challenges and conflicts. I came to an understanding that this process was often highly medicalised with detailed discussions about complex medical treatments, which are distant

from the emotional journey of parents. This resulted in differing views between parents and NICU staff leading to complex ethical challenges, and at times legal issues. While there was increasing evidence about decision-making in neonatal intensive care, no exhaustive descriptions of the parental lived experiences of newborn death was found in the literature. I felt this was a major gap and potentially is the reason for persisting conflicts between parents and professionals, despite extensive frameworks and guidelines being in place. Similarly, while research had focussed extensively on the ethical issues and decisions faced by the NICU staff, very little attention had been paid to understanding their views and experiences as they manoeuvred supporting grieving parents and caring for a sick newborn baby. It was a result of my interest and the apparent unmet need that I conceived this PhD study.

1.1 SUMMARY OF THE PROBLEM

While the United Kingdom (UK) is one of the safest countries in the world in which to give birth (1), in 2021, the neonatal (or newborn) mortality and infant mortality rate was recorded as 2.7 and 3.7 deaths per 1000 live births (2). With advances in neonatal intensive care in the UK and other high-income countries, it has become possible to ‘prolong life’ almost ‘indefinitely’ using advanced life-support systems and medications. This has the potential to raise parental expectations about the benefits of neonatal intensive care. Almost all (98%) (3) newborn deaths in the UK now occur because of withdrawal of LST(4) in the NICU, a decision that is taken by the clinical team in discussion with parents. Professional associations like the Royal College of Paediatrics and Child Health(5) (RCPCH) and British Association of Perinatal Medicine(6) (BAPM) have developed frameworks for when the withdrawal of LST may be ethically and legally permissible. They recommend that decisions should be centred on the child’s best interests, requiring considerations beyond clinical context to that of the family’s situation in its entirety. A shared decision-making model dominates the policy and practice guidelines, reflecting the NHS’s commitment to person-centred care(7). The inherent expectation here is that by following the ‘correct’ process, conflicts can be avoided in such

problematic situations(8). While these models and frameworks are extremely useful for standardisation, their interpretation varies, and practical implementation is even more complex. As a result, conflicts between NICU staff and parents are not uncommon, and sometimes may lead to legal process, and a 'lose-lose' situation for everyone involved, including the sick newborn.

The manner in which death and bereavement processes are dealt within the NICUs can have lasting effects on the physical and mental health of the parents[8,9] as well as familial relationships and harmony(9). This is particularly important when dealing with a multicultural and diverse population with a wide range of ethnicities and religious beliefs, as in the UK. A retrospective quantitative analysis of medical records from a NICU in the UK showed that ethnicity had an influence on decisions to withdraw LST from very unwell newborn children(10). The study showed that while nearly all White parents agreed to the withdrawal of LST, only 54% of Black African parents agreed to the same, due to religious and personal beliefs(10). The authors also commented on the likelihood of similar reasons contributing to a relatively lower rate of do-not-resuscitate orders in babies of Black African parents(10). The recent Perinatal Mortality Surveillance Report from Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK) showed that newborn death rates were higher by 43% for Black and Black-British babies(11) and 59% higher for babies of Asian and Asian-British ethnicity(12) when compared with White babies. Despite these stark differences, there is no guidance about the role of culture and beliefs in grief and bereavement from newborn death. Overall, there is limited evidence concerning the lived experiences of parents whose baby dies in a NICU, and the staff who support them.

In the following paragraphs, I provide a brief introduction to the phenomenon of newborn death and parental grief, distress and the dilemmas faced by NICU staff, the potential and importance of this study, followed by the aim and objectives of the study and an outline of the thesis.

1.2 NEWBORN BEREAVEMENT AND ITS IMPACT ON PARENTS

In the neonatal unit, parents of critically ill newborns may experience a wide range of emotions, from the shock of admission, to observing the use of intensive and unfamiliar technology and treatments and eventually death from withdrawal of LST (13). Anticipatory grief may be experienced by parents, involving forms of coping prior to death, managing emotional conflicts and facilitating preparedness(14). Providing timely and appropriate supportive care to parents, prior to the baby's death, is essential in helping to manage their grief and its downstream effects. With the majority of child deaths in the UK occurring in the newborn period (3), it is important to develop competence in providing appropriate and tailored bereavement care. For NICU staff, better insights into the parental experiences will enable them to engage more meaningfully with parents as they cope with anticipation of their newborn's death, while also continuing to ensure appropriate care for the baby.

From a medical perspective, newborn deaths occur primarily in three different situations, (i) ante-natally diagnosed lethal congenital malformation, where parents refused termination of pregnancy; (ii) babies born at the limits of viability (22 to 24 weeks) and the associated complications resulting from preterm birth; and (iii) unexpected birth related brain injury (neonatal encephalopathy) following a full-term pregnancy. The intensity and duration of parents' grief and experiences are likely to be influenced by mode of their child's death as well as characteristics of parents such as gender or ethnicity and that of the deceased child, such as age (15).

Ensuring as little stress as possible (medically) for infants at the end-of-life is not only important for parents but also for NICU staff. End-of-life care for critically ill newborns has been highlighted as a concern by neonatal nurses(16) and the Royal College of Nursing has repeatedly expressed worries over lack of time reported by intensive care nurses to address these issues(3). Managing stress for infants and their families involves identifying the family's religious and spiritual needs and thereby facilitating a dignified and peaceful death. It also

includes advance-care planning and understanding parents' preferred place of end-of-life care. For instance, some cultures recognise the beginning of life (soul) at 12 weeks of gestation, and therefore withdrawal of LST from even an extremely premature infant may not be acceptable. Advance care planning helps to develop mutual understanding of medical, social and legal frameworks for any decisions that need to be made about critical care(17) and potentially avoid conflicts causing further trauma and distress to those involved, especially parents.

1.2.1 GRIEF AND NEWBORN DEATH

Grief is defined as a natural reaction in response to a loss(18). Grieving and bereavement are among the most natural and fundamental experiences of human lives, embedded in the personal relationships, emotions, and expectations that one develops as part of social life. Of all the social relationships and possible bereavements, death of a loved one is generally thought to be one of the most painful and distressing. Bereavement research over the years has shown that while some individuals may have resilient coping mechanisms for their grief(19), for many others this experience can be very problematic, prolonged and painful.(20)

Bereavement of any kind is stressful, whenever it occurs. Newborn death is complex and commonly not talked about. Society often deems it as less significant than death of an older child, spouse, sibling or parents, and as a result parents of a newborn baby who dies may feel disenfranchised(21). Kenneth Doka introduced the concept of disenfranchised grief to describe grief that is not publicly mourned, acknowledged, or supported(22). It often causes a conflict between the need for grieving by the bereaved individual and denial of the opportunity to grieve publicly, potentially causing suppression of emotions, higher risk of depression and withdrawal from society(23). Research has shown grieving over the death of a child is more likely to be complicated and debilitating for parents(24-26), potentially due to lack of preparation time as most child deaths occur during infancy(27). Moreover, with advances in medicine and social care, child deaths have become relatively uncommon. In a world where

infant death is uncommon, its effects may be more profound than when and where infant death is common. A child's death, in these circumstances, may be experienced as the death of parents' dreams and aspirations(28). For example, a child's death could prompt the loss of an individual's sense of being a parent or a loss of shared parental relationship. Parents may struggle to come to terms with their sense of guilt due to a perceived failure of protecting their child and they may continue to suffer as they live through the milestones their deceased child would be reaching.

Paradigms about grief have evolved over the last century. A predominant trend in psychological research for many years considered grieving as a universal process, which is not only consistent across age groups, by all kinds of bereavement, relationships, cultural groups etc., but also one that can be understood independently of the socio-cultural context. In the classical literature the bereaved would have to relinquish the deceased in order to heal the loss, whereas the postmodern constructivist theories focussed on continuing the relationships with the dead and reconstruction of meaning(29). Separation of an individual's grief from its context brought an understanding that grief occurs primarily within one individual and that individual may suffer illness or 'psychological deficits'(30). Each loss is as unique as the individual experiencing it. Therefore, in order to support parents optimally through their grief in the NICU, the staff working with parents need to consider the context and understand how it impacts on the life functioning of bereaved parents(31). Although this thesis is not rooted in the theoretical framework of grief theory, I believe it is important to gain a basic understanding of the predominant theoretical models, as it may help in understanding parent's grief and coping processes. Paradigmatically, grief theory is broken down into the three major categories of task-based, stage-based, and post-modern/contemporary perspectives. These are considered briefly below.

1.2.1.1 GRIEF THEORY

In the early 20th century, Freud's psychoanalytic theories laid the foundation for grief theory and research(32, 33). He explained that mourning process takes time after the bereavement

and interference in this process may be harmful. He documented that in addition to its own unique and distinct symptoms, grief may resemble some other syndromes such as depression and anxiety(29). Overall, Freud suggested that in the normal mourning process, the bereaved will overcome their loss by dissolving the memories of deceased and accepting the reality that they are no longer present(33). With disregard to one's personal identity, physical surroundings and socio-cultural influences(34), more focus was bought upon intrapsychic and cognitive processes, and pathologizing those who did not relinquish relationships with the deceased(35). This understanding was later challenged, giving a more holistic view to understanding bereavement and grief.

Elizabeth Kübler-Ross (1969) introduced a new perspective of grief and stages of loss with her extensive work with people suffering from terminal illness, later extended to include any form of catastrophic personal loss, including the death of a loved one. In her work on Death and Dying(36), she challenged clinicians and other healthcare staff to consider the perspectives of patients who are nearing death. She encouraged empathic listening instead of imposing their thoughts on patients and silencing their worries and proposed a comprehensive pathway (stages) of dying and grieving process. The five stages included, denial, anger, bargaining, depression and acceptance (and were later clarified to apply to bereaved population) (35). Although these stages may neither be linear not necessarily experienced by everyone, Kübler-Ross suggested most individuals will experience at least two of them(37).

John Bowlby, another stage-based theorist, was recognised for his work on attachment theory. He proposed that in order to understand grief, we need to understand the role of loss of relational attachments, and his hypothesis included an individual undergoing four phases-numbing, yearning and searching, disorganisation and reorganisation(38).

Stroebe and Schut (1999) challenged the previous theories and the need of bereaved individuals to confront their experience in order to accept the truth and avoid detrimental

consequences. They challenged these notions with the possibility that some people may need to adopt non-confrontational approaches of coping and proposed the Dual Process Model (DPM) of coping with bereavement, which differentiates between the two mechanisms/strategies of coping: loss-oriented and restoration-oriented(39). The loss-orientation strategies include the need of bereaved to yearn and reminisce for the deceased, whereas restoration-oriented acts would include the bereaved individual's need to take time off from the pain and to engage in everyday life needs as an attempt to embracing their new identity. While loss-oriented component was considered more 'feminine' among many cultures, as against restoration-oriented that was perceived to be more 'masculine'(39), the DPM proposes that bereaved individuals oscillate between the two(40).

Finally, it is important to discuss one of the popular constructivist theories, that of Robert Neimeyer (1999), i.e. the meaning reconstruction approach. Neimeyer disagreed with the traditional grief models that imply similar emotional reactions of all grieving individuals. The approach acknowledged the idiosyncrasies of each individual that adds to the uniqueness of their grief and even though grieving may be a personal process, he suggests that the role of societal and contextual factors must be considered in understanding and addressing it. Meaning making is a process deeply intertwined with one's ongoing interaction with the social world(41). Our social world, beliefs and value systems shape our meanings as well as the process of grieving. Therefore, meaning making in the wake of bereavement is a not merely a cognitive process but one that requires social validation for changed, newly formed identities(42).

A basic understanding of the prominent grief theories is important as it helps to bring a perspective and structure while understanding parental grief. This will aid in our exploration of parental experiences of newborn death and their bereavement journey as well as in understanding the support parents need in their grief.

1.3 DISTRESS EXPERIENCED BY PROFESSIONALS

It is important to acknowledge that like all human beings, NICU staff are shaped by their social and cultural backgrounds. Previous research involving NICU staff has focussed primarily and extensively on the ethical issues and decision-making, presenting a very narrow view to the range of events and emotions experienced. Very little attention has been paid to understanding the lived experiences of staff, of newborn death and of its clinical implications(43, 44).

In neonatology, the ability of NICU staff to identify the need for sensitively engaging and supporting bereaved parents, (45, 46), using the appropriate language and timing and mitigating the traumatic reactions(47), has long been recognised. However, newborn death is also a stressful and emotionally demanding time for staff themselves, as they deal with ethical dilemmas and moral distress, while caring for sick and terminally ill newborns and comforting grieving parents, dealing with birth and death within a very short span of time(48, 49). Studies within paediatric intensive care environments have shown that physicians are vulnerable to a sense of guilt and feeling of powerlessness(50), while juggling with questions of ‘what is the right thing to do?’ between a chance at life or against a poor quality life with severe disabilities, as well as institutional constraints(51). We also need to consider the potential long-term impact on NHS of requiring increased intensive care capacity and expensive resources to maintain life(52), increased work absenteeism and burnout due to the burden of moral distress(53). Intensive care nurses also experience distress when they are not able to provide dignified, peaceful and timely death for their patients(54). Not addressing this excessive emotional involvement carries the risk of vicarious traumatisation(55). Understanding staff’s experiences of caring for newborns who die in the NICU and supporting grieving parents is important from two aspects, i.e. to understand how the experience impacts them and the support they extend to grieving parents.

1.4 IMPORTANCE OF THIS RESEARCH

Bereavement, especially after a child's death, can disrupt the understanding of life in a profound and pervasive manner of those affected. Studies have shown detrimental effects of a child's death on parents' physical (hospitalisations, chronic conditions, heightened maternal mortality, etc.) and mental health (depression, anxiety, dissociation, interpersonal sensitivity, aggression, and post-traumatic stress disorder)(56, 57). Bereavement following the death of a child has been shown to have a negative impact not only on individual parent's health, but also on parents' relationship with each other(9). In the UK, parents are encouraged to be involved in the decision to withdraw LST(6). Managing parental involvement in treatment decisions can also exacerbate conflicts between parents and professionals(49). NICU processes often complicate parental grief and those who have experienced newborn death might be at a greater risk of developing complications in the grieving process when compared with other types of bereavement and loss(58, 59).

Very little is known about parents' experiences of both anticipatory grief and the newborn's death with or without specific support from perinatal palliative care team. The National Institute for Health and Care Excellence (NICE) has pointed to the need to understand the impact of newborn death and end-of-life care on parents' psychological health and relationships with each other. Due to a dearth of scientific evidence in this area, the severity of parental distress as well as barriers and facilitators of grief and coping is not well understood scientifically(3). Moreover, these are key components of advance care planning and have potential to reduce the likelihood of negative health outcomes in bereaved parents, souring of parent-staff relationships and the emotional distress experienced by professionals(3, 60).

To summarise; in order to design the appropriate supportive care strategies, we need to have a more in-depth understanding of how these factors may influence experiences and move from a formal theory-building process to capturing the holistic nature of lived experience.

Qualitative enquiry offers the opportunity to understand in-depth the lived experiences of bereaved parents in the surrounding context of NICU environment and staff.

1.5 AIMS AND OBJECTIVES OF THE RESEARCH

1.5.1 AIMS

The primary aim of this analysis is to offer an in-depth account of parents' experiences of newborn death in the UK, within the context of the clinical encounter, understanding the emotional and personal accounts of parents, their experiences and perceptions of communication and support while in the neonatal intensive care unit and after, and their process of bereavement and grief. A secondary aim is to better understand views and beliefs of neonatal staff (both doctors and nurses) about newborn death and their experiences of providing care for newborn babies and their parents, with the goal of identifying opportunities for improved support for parents.

1.5.2 OBJECTIVES

Specific objectives of the study are listed below:

1) To synthesise existing qualitative research literature related to parental experiences of newborn death in neonatal intensive care units to gain better understanding of those parental experiences.

2) To explore parents' lived experiences of bereavement and newborn death in the UK, time spent in the neonatal intensive care unit, death, and their bereavement journey.

3) To explore NHS NICU staffs' lived experiences of caring for admitted newborns who died in the neonatal intensive care unit and working with bereaved parents through this process.

4) To synthesise and discuss the data from analysis of lived experiences of parents and NICU staff and develop recommendations for practice and research.

1.6 OUTLINE OF THESIS

The thesis is comprised of seven chapters. An overview of all chapters is presented below:

CHAPTER ONE has introduced the research idea, summarised the problem and provided some context in relation to experiences and grief from newborn death.

CHAPTER TWO presents a meta-synthesis of qualitative literature on parental experiences of newborn death. This will help to contextualise the study and highlight gaps in knowledge.

CHAPTER THREE provides detail regarding the theoretical background to the study and the rationale for the use of hermeneutic phenomenology. It discusses the reflexive journey I have undertaken as part of this study. Thereafter, it describes the study design and methods used in the study.

CHAPTER FOUR provides the findings of the study on parental lived experiences and the parent's narratives of NICU and bereavement and presents the interpretation and meaning with the emergent phenomenon.

CHAPTER FIVE focusses on the lived experiences of NICU staff of newborn death and supporting parents. Interpreted themes and phenomenon are presented in this chapter.

CHAPTER SIX synthesises and discusses the study findings, re-contextualising them in relation to existing evidence and practice. A comprehensive understanding of NICU experiences is presented that supports development of recommendations, along with the identified study strengths and limitations.

CHAPTER SEVEN concludes the thesis presenting its contribution to knowledge with a discussion of my own reflexive journey.

CHAPTER 2- ABSENCE OF RELATIONAL CARE: A META-SYNTHESIS OF PARENTAL EXPERIENCES OF NEWBORN DEATH AND BEREAVEMENT

2.0 INTRODUCTION

Death of a baby is usually a devastating experience for parents. Evidence suggests that parents who have experienced newborn death are at a greater risk of developing complications in the grieving process compared with other types of bereavement and loss(9). Studies have shown detrimental effects of a child's death on parent's physical health (hospitalisations, chronic conditions and heightened maternal mortality) (56, 57) as well as negative mental health outcomes (depression, anxiety, dissociation, interpersonal sensitivity, aggression, and post-traumatic stress disorder) (56, 61).

Understanding experiences of bereaved parents will help in providing appropriate support to these families and in improving neonatal care. Qualitative research approaches are best suited for this purpose as they allow full exploration of the patients' experiences of their baby's death. Evidence on parental decision-making in neonatal intensive care and about bereavement support for parents has been accumulating. However, a systematic analysis of the holistic experience that parents undergo from childbirth to NICU admission, decision-making when babies are critically unwell, deterioration and bereavement during the neonatal stay, has not been conducted. The purpose of this review is to synthesise the existing qualitative literature about experiences of parents related to the death of their newborn infant.

2.0.1 OBJECTIVE

To synthesise existing qualitative research literature related to parental experiences of newborn death in neonatal intensive care units to gain better understanding of parental experiences.

2.1 METHODS

2.1.1 SEARCHING FOR STUDIES

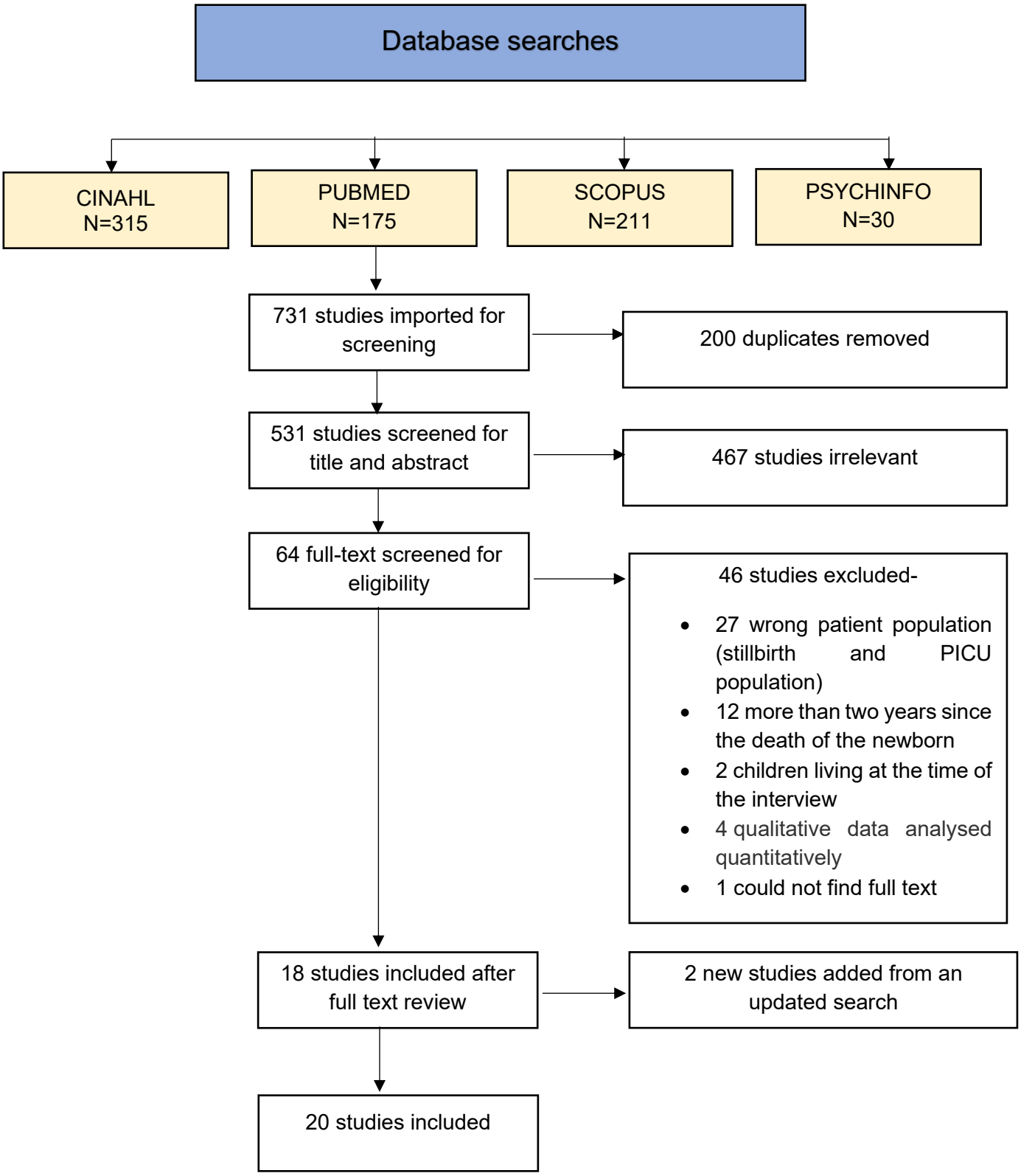
The criteria for inclusion and exclusion of studies were determined after discussion with supervisors. All original research articles reporting qualitative and mixed-methods (when there is sufficient qualitative data) studies focussing on the experience of parents around the death of their newborn infant in a neonatal intensive care environment, were included. Studies published only in the English language (due to reviewers' lack of knowledge of any other language) were included and no date restrictions were applied, as older studies may still be relevant for analysis. However, a restriction of 2 years since newborn death was employed to utilise maximum recall value of participants' experiences.

The search process comprised of scoping the existing literature to develop search strategies before a formal main stage of data search. The scoping stage was informal and exploratory and guided the identification of Medical Subject Headings (MESH) and a preliminary search was performed for trial purposes. The final literature search strategy was developed following guidelines recommended by the Cochrane Qualitative Research Methods Group and employed multiple sources and methods of data search. The following databases were used: PubMed- National Institute of Health, Cumulated Index to Nursing and Allied Health Literature (CINAHL), PsycINFO- American Psychological Association and Scopus. These four databases have been described as providing up to 93.1% of retrieval of qualitative research publications(62). To further the chance of relevant studies being retrieved, reference lists of all studies from the final sample were scanned for any other eligible studies.

2.1.2 SELECTING STUDIES

The process of selecting the studies was iterative. Initially I undertook the search for studies independently, which was later duplicated by an independent researcher for the purposes of validation (see appendix 1 for search strategy). The total number of published works retrieved was 731, of which 531 studies remained after scanning and removal of duplicates. A majority of these works were excluded after screening the title and abstracts, because either they were irrelevant to the research objective or did not have a qualitative research component. Where this was not clear, the full text was read. In case of lack of certainty, clarifications were sought from supervisors. For example, initially all studies that included death of infants up to 1 year of age were included as they also reported data from newborn death. However, following full text review, it was decided to exclude these papers because it was difficult to distinguish data reported from parents of newborn babies who died in the NICU versus older infants who died in the paediatric intensive care unit. The first extensive search was performed between November 2021 and February 2022, which generated 18 results. The search was updated in April-May 2023, which added two new results to the synthesis, therefore resulting in 20 papers included in this meta-synthesis [Figure 1]

Figure 1- PRISMA Flow Diagram of Study Identification and Selection



2.1.3 DATA SYNTHESIS

Thematic analysis, following the Thomas and Harden approach(63), was used to synthesise and analyse the data. This approach was chosen as it facilitates the researcher in conducting the analyses in pragmatic steps, enables transparent audit and encourages researcher connectiveness to the data. It involved three stages. The first stage involved data extraction through line-by-line coding of data from the primary studies and organising them in NVivo software. The codes were then grouped into categories based on commonality. In the second stage, categories and codes were integrated and broad descriptive themes were developed. At this point, data were exported into Microsoft word documents. Finally, in the third stage, an attempt was made to 'go beyond' the descriptive themes, by bringing in integration and interpretation. New theoretical insights were generated in terms of analytical themes and were validated and finalised in discussion with research supervisors. An independent reviewer was involved at each stage and any discrepancies or disagreements were resolved through discussion with supervisors.

2.2 FINDINGS

2.2.1 DESCRIPTION OF THE STUDIES

The 20 papers in the final full synthesis represent the views of parents from 11 countries (Australia [x1], Canada [x1], England [x2], France [x1], Iran [x2], Jordan [x2], Netherlands [x1], Norway [x1], Scotland [x1], Switzerland [x2], USA[x6] and included data from more than 740 participants (minimum 2 and maximum 194). While there was a representation of various ethnicities, the majority of the participants were white. Data were collected in the form of interviews, participant and non-participant observations, digital conversation recordings and surveys (please refer to table 1 for details of all the studies included). Four studies utilised a mixed-methods approach and one of the studies analysed qualitative data using SPSS. However, all the five studies contained pertinent qualitative data that were well reported enough to be suitable for analysis. Some studies also included experiences of hospital staff,

such as NICU doctors and nurses. For the purposes of this meta-synthesis's research question, these data were not included in the analysis. Other than the one study that was published in 1981, all of the included studies are between 2000-2021. Table 1 summarises the characteristics of the selected studies.

Table 1- Summary of Qualitative Studies of Parental Experiences of Newborn Death

Author(s)	Title of paper	Year	Methodology	Data collection	Theoretical framework	Aim	Countries	Sampling approach	Analysis Approach	Participants
Aagaard, H., et al	Losing one twin in the NICU - A case study of the parental experience	2016	Qualitative case study	In-depth interviews	Not given	To generate a deeper understanding of parents' experiences of losing one twin in the NICU	Denmark	Purposive sampling	Thematic analysis	2
Razeq, A., et al	Maternal Bereavement: Mothers' Lived Experience of Losing a Newborn Infant in Jordan	2018	A qualitative descriptive phenomenological approach	Semi structured face-to-face interviews	N/A	To understand bereavement and its associated meanings as lived and experienced by the mothers who lost their newborn infants in the intensive care units of hospitals in Jordan	Jordan	Purposive sampling	Thematic analysis	12
Abraham, A., and Hendricks, M. J.	" You Can Only Give Warmth to Your Baby When It' s Too Late" : Parents' Bonding With Their Extremely Preterm and Dying Child	2017	Qualitative study.	Interviews with Ethnographic aspects (temporary field stays, minimal observations)	Symbolic interactionism, with its focus on the reconstruction of subjective meaning	To understand parents' perspectives of end-of-life decision making in extremely preterm infants at the limit of viability	Switzerland	Purposive sampling	Hermeneutically oriented qualitative content analysis guided by Kuckartz' s approach.	20
Brinchmann, B. S., and Vik, T.	Parents' Involvement in Life-and-Death Decisions in Neonatal Intensive Care: Norwegian Attitudes	2005	Mixed methods	Survey and un-structured in-depth interviews	Grounded theory	To discuss the general view of parents' role in life-and-death decision making concerning very premature babies in Norway	Norway	Not mentioned	Content analysis	35

Author(s)	Title of paper	Year	Methodology	Data collection	Theoretical Framework	Aim/Purpose	Countries	Sampling approach	Analysis Approach	Participants
Razeq, A., et al	Informing mothers of neonatal death and the need for family-centered bereavement care: A phenomenological qualitative study	2021	A qualitative phenomenological approach	Semi structured interviews	N/A	To understand the lived experience of mothers surrounding the time of being informed of neonatal deaths in intensive care units.	Jordan	Purposive sampling	Interpretive phenomenological analysis	12
Hasanpour M., et al.	Parental needs in infant's end-of-life and bereavement in NICU: A qualitative study	2016	Qualitative study	Semi-structured interviews	Not given	To explore of parental needs in infant end-of-life and bereavement.	Iran	Purposive sampling	Qualitative content analysis	11
Hendriks, M.J. and Abraham, A.	End-of-Life Decision Making for Parents of Extremely Preterm Infants	2017	Hermeneutically oriented qualitative research.	In-depth interviews	N/A	To explore parental attitudes and values in the end-of-life decision-making process of extremely preterm infants (gestational age < 28 weeks).	Switzerland	Purposive sampling	Kuckartz's approach of content analysis	20
Kavanaugh, K., et al.	Life Support Decisions for Extremely Premature Infants: Report of a Pilot Study	2005	Collective case study method	tIn-depth interviews	Ottawa Decision Support Framework	To describe decision making and the decision support needs of parents regarding life support decisions made over time prenatally and postnatally for extremely premature infants.	USA	Convenience sampling	Framework approach	8

Author(s)	Title of paper	Year	Methodology	Data collection	Theoretical Framework	Aim/Purpose	Countries	Sampling approach	Analysis Approach	Participants
McHaffie, H. E., et al	Lingering death after treatment withdrawal in the neonatal intensive care unit	2001	Qualitative with the use of SPSS	Face to face interviews	Not given	To explore parents' perceptions of treatment withdrawal and the dying process.	Scotland	Purposive sampling	Descriptive content analysis	118
Moro, T.T., et al.	Parent Decision Making for Life Support for Extremely Premature Infants: From the Prenatal Through End-of-Life Period	2011	Collective case study	Tape-recorded interviews	Ottawa Decision Support Framework	To describe how parents make life support decisions for extremely premature infants from the prenatal period through death from the perspectives of parents, nurses, and physicians	USA	Purposive sampling	Framework approach	5
Orfali, K	Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units	2004	Comparative ethnographic study	Participant observation and in-depth interviews.	Sociology of experience	To study the parental role in decision-making within two technologically identical but culturally and institutionally different contexts: France and the United States.	France and USA	Case based approach	Comparative-case based analysis of ethnographic data	71
Pector, E., A	Views of Bereaved Multiple-birth Parents on Life Support Decisions, the Dying Process, and Discussions Surrounding Death	2004	Mixed-methods approach	Narrative e-mail survey	Grounded theory approach for qualitative data	To study the experiences of bereaved parents of multiples with resuscitation and life-support discussions, the death process, and conversations with health-care professionals about death.	USA	Purposive sampling	Modified grounded theory approach	71

Author(s)	Title of paper	Year	Methodology	Data collection	Theoretical Framework	Aim/Purpose	Countries	Sampling approach	Analysis Approach	Participants
Sadeghi, N., et al.	Spiritual Needs of Families with Bereavement and Loss of an Infant in Neonatal Intensive Care Unit: A Qualitative Study	2016	11	Semi-structured interviews	N/A	To explore the spiritual needs of families in Iran at the end of their baby' s life and through bereavement in the NICU.	Iran	Purposive sampling.	Qualitative content analysis	11
Shaw, C. et al.	Parental involvement in neonatal critical care decision-making	2016	Qualitative study with conversation analysis approach	Digitally recording all formal conversations t	Social action theory	To explore the process of shared decision-making in the neonatal unit.	England	Purposive sampling	Conversational analysis approach	18
Thornton, R., et al.	Creating evidence: Findings from a grounded theory of memory-making in neonatal bereavement care in Australia	2020	Grounded theory	Semi-structured interviews	Grounded theory approach informed by Corbin and Strauss	To explore the significance of memory-making for bereaved parents and the impact of memory-making on parents' experience of loss following neonatal loss.	Australia	Theoretical sampling	Thematic analysis using constant comparison	18
Manen, M.A.V.	On Ethical (In) Decisions Experienced by Parents of Infants in Neonatal Intensive Care	2014	Hermeneutic Phenomenology	Interviews	N/A	To explore the phenomenon of the ethical decision from the perspectival experience of parents caring for their child.	Canada	Purposive sampling	Thematic analysis using analytic reflection	14

Author(s)	Title of paper	Year	Methodology	Data collection	Theoretical Framework	Aim/Purpose	Countries	Sampling approach	Analysis Approach	Participants
Vermeulen, E.	Dealing with doubt: Making decisions in a neonatal ward in The Netherlands	2004	Ethnography	Non-participant observation	Not given	To describe decision-making concerning children born very prematurely	Amsterdam	Purposive sampling	'Thematic analysis	40
Wocial, L.,D.	Life Support Decisions Involving Imperiled Infants	2000	Descriptive qualitative study	Interview	N/A	To explore parents' perceptions of the decision making process	USA	Purposive sampling	Content analysis	20
Redshaw, M., et al	This is time we' ll never get back' : a qualitative study of mothers' experiences of care associated with neonatal death	2021	Mixed methods	Survey methodology with open questions and space for free text responses in the end	N/A	To explore the perceptions and experience of women whose baby died in the neonatal period about their care in the perinatal period, on delivery suite, in the neonatal unit and afterwards, expressed in their own words.	England	Purposive sampling	Thematic analysis	194
Mahan, C.K., et al.	Neonatal Death: Parental Evaluation of the Nicu Experience	1981	Mixed methods	Survey-Questionnaires filled in by mothers and fathers.	N/A	To evaluate methods of helping families through this highly vulnerable time and to see if the idea of parental support systems concurs with the feelings of those affected by NICU care practices.	USA	Purposive sampling	Descriptive analysis	46

2.2.2 QUALITY ASSESSMENT

The Critical Appraisal Skills Programme qualitative checklist(64) (CASP) was used to assess systematically the trustworthiness and relevance of published data. Being one of most widely used tool for qualitative literature reviews, CASP consists of 10 items using a clear checklist. The quality of each study was categorised on each question as Yes, No, or Can't tell. Assessment was done by a single reviewer, and later confirmed for all papers by an independent reviewer. Any discrepancies were discussed and resolved after discussion. Although use of the CASP checklist for appraisal of qualitative studies is debated(65), the categories included in the checklist allowed me to engage with the concepts of transferability, transparency, reflexivity and rigour of each study that was included.

The appraisal showed that all the research designs were chosen appropriately to suit the original research objectives as well as participant population. In all but one study, methods were adequately described. All studies clearly reported the results. Five studies did not report ethical considerations, of which one study mentioned not obtaining ethical approvals due to minimal risk. Only five studies reported aspects of reflexivity and researcher bias. Quality appraisal was not performed to determine inclusion or exclusion of studies, but to gain a deeper insight into methodological aspects of each of the study included. A complete tabular presentation of the quality assessment is shown in Table 2.

Table 2- Quality Appraisal of Primary Studies Using the CASP Qualitative Checklist (Critical Appraisal Skills Criteria Programme).

Author, Year	CASP questions									
	1	2	3	4	5	6	7	8	9	10
Aagaard, H., et al., 2016	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Abraham, A., and Hendriks, M. J., 2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Brinchmann, B. S., and Vik, T., 2005	Y	N	Y	C	Y	N	C	Y	Y	Y
Hasanpour M., et al., 2016	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Hendriks, M.J. and Abraham, A., 2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Kavanaugh, K., et al., 2005	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mahan, C. K., et al., 1981	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Manen M.A.V., et al., 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
McHaffie, H., E., et al., 2001	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Moro, T.T., et al., 2011	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Orfali, K. 2004	Y	Y	Y	Y	Y	N	C	Y	Y	Y
Pector, E. A., 2004	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Razeq, A., et al., 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Razeq, A., et al., 2021	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Redshaw, M., et al., 2021	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Sadeghi N., et al., 2016	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Shaw C., et al., 2016	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Thornton, R., et al., 2020	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Vermeulen, E., 2004	Y	Y	Y	Y	Y	Y	C	Y	Y	Y
Wocial, L. D., 2000	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Note: **Y** = Yes; **N** = No; and **C** = Can't tell. 1=Was there a clear statement of the aims of the research? 2 =Is the qualitative methodology appropriate? 3=Was the research design appropriate to address the aims of the research? 4=Was the recruitment strategy appropriate to the aims of the research? 5=Were the data collected in a way that addressed the research issue? 6=Has the relationship between the researcher and participants been adequately considered? 7=Have ethical issues been taken into consideration? 8=Was the data analysis sufficiently rigorous? 9= Is there a clear statement of findings?10=How valuable is the research?

2.2.3 THEMES AND ANALYSIS

The findings of this meta-synthesis are presented as ten emerging concepts and three final themes (Table 3): - 1) Transcending life and death: parents' need for physical closeness; 2) Empowering or paternalistic: shared decision-making regarding withdrawal of life-sustaining treatment (or LST) and; 3) Compassionate care: parents' needs from communication with staff.

Table 3- Metasynthesis Analytical Themes

Theme 1- Transcending life and death: parents' need for physical closeness		
Emerging themes	Initial concepts	Relevant papers
Parents need for closeness and physical touch with baby	- Visiting baby in the NICU- sometimes also experienced as a burden; - Touching the baby and need for physical contact; Bonding with their baby, singing and reading to them as a highly valued that time.	(66-68)
Separation from the baby	- Separation from baby followed a traumatic birth; - Hospitals not being a woman-centred environment; - Having limited access to the baby; - Intense emotional impact of separation; - Separation hindered bonding and creating memories with their baby; - Distressing experience seeing other mothers with their babies in the postnatal ward.	(66-70)
Impact of NICU environment on closeness	- Non-parental care for baby due to dependence on staff; - Fathers often occupied with administrative tasks; Incubator acting as a barrier between parent and baby; - Parents' need to feel recognised by staff as parents and as important for baby	(66, 68, 71, 72).
Caring for their dying baby	- Spending time with baby during death; - Role of physical closeness in acceptance of death; Guilt and regret for not spending time; - Cultural restrictions on mothers. - Gratitude in retrospect when able to embrace closeness.	(66-69, 71-75)
Theme 2- Empowering or paternalistic: Shared decision-making regarding withdrawal of life-sustaining treatment		
Emerging themes	Initial concepts	Relevant papers
Parental choice	- Being involved in the decision was important; - Most parents wanted to save their baby at any cost; Some did not want to see their child suffering; - Overall parents needed to be well informed, listened to and included in decision-making.	(72-81)

Parental state of mind (pressure)	- Distressing and overwhelming situation; - Accumulating continuous information; - Dissociative state of mind; - Evaluating the consequences, feeling the burden and emotional conflict.	(72, 74-78, 81, 82)
Collaborative decision making - Recommendations vs options	- Is there really a choice?; - Language used by clinicians "best interest of baby"; Clinicians recommendations rather than options; Presented as a collaborative act but is it?; - Pressurised parents; - Impact of a trusting relationship with staff and choice of words.	(72-77, 79-81, 83)
Theme 3- Compassionate care: Parents' needs from communication with staff		
Emerging themes	Initial concepts	Relevant papers
Understanding parent's needs	- Role of empathy and compassion; - Parents appreciated when staff made efforts to understand their needs (emotional, spiritual, physical etc) and make effort to address those needs; - Role of memory making.	(66-68, 70, 72, 78, 82, 84, 85)
Communication with staff	- Parents needed and appreciated direct and honest communication; - Role of timely communication and recognition of gravity of the matter (need to feel the urgency in staff in responding); - Respectful communication; - Lack of appropriate communication equates to lack of support (medical jargons etc); - Role of non-verbal communication and gestures	(66, 67, 70-72, 74, 76-79, 82)
Continuity and consistency	- Crucial nature of consistency in communication; - Impact of lack of continuity on parental experience.	(68, 71, 77, 78)

2.2.3.1 THEME 1- TRANSCENDING LIFE AND DEATH: PARENTS' NEED FOR PHYSICAL CLOSENESS

The first theme of this metasynthesis is about parents' need for closeness and experiencing physical contact, which was a core aspect of parenthood in the NICU. Separation was difficult and being physically close to the baby during the NICU days as well as after, was a coping mechanism through their anticipatory grief and bereavement. This theme shows how the

parental need for touch and physical closeness with the baby was not only present during baby's birth and life but sustained during bereavement and after death.

2.2.3.1.1 DESIRING PHYSICAL TOUCH WITH BABY

Parents longed for the physical closeness with their baby, throughout the NICU period. Studies reported that parents used any opportunity that was presented to them to be with their baby in the NICU(66-68). Experiences of touching and holding their baby, were accompanied by talking to them, singing rhymes and songs, and reading stories(66, 72). Spending time with their baby brought them joy and allowed them to express their love. Despite the physical barrier caused by the incubator, they cherished the limited time they had for experiencing physical closeness with the baby(66).

> *"It's one of my nicest memories that I was reaching [into the incubator] and the little one was holding my finger with his little hand. That was beautiful."* (Mother)(66).

2.2.3.1.2 SEPARATION FROM THE BABY

In all the included studies, NICU admission was an emotionally daunting experience for parents. One of the main reasons described was the sudden separation of parents from the baby after birth. In order to address the criticality and urgency of situation baby was often taken immediately into the NICU for treatment and parents were not able to have the desired time and skin-to-skin contact with the baby. It was more traumatic for mothers because in many instances their movement was restricted due to a traumatic birth or a caesarean section and they had to wait to meet their baby, whereas fathers were able to accompany the baby to the NICU and remain closer to the baby during examination and NICU admission(66-68).

> *"I just wanted to be moved to where my baby was, but instead I had to stay in a room with an empty cot."* (Mother)(68)

Restricted access to the baby due to clinical interventions intensified the reality of separation once the mother was discharged from the hospital while the baby remained in the NICU.

Traveling back and forth to spend limited time with the baby in the NICU was an additional stress factor for the parents(66). The stress of having limited access to their own child also hindered their bonding experience. Moreover, seeing other mothers in the postnatal ward with their babies accentuated their feelings of loss and separation. It was a distressing experience for all mothers who were placed in this situation. They felt it was inconsiderate of staff and shared how isolating it was as they tried to maintain hope and a positive mindset(68-70).

> *"I felt the loss and devastation when they admitted another patient with her baby in the same room: [the baby] was crying and suckling milk from his mom."* (Mother)(69)

2.2.3.1.3 IMPACT OF NICU ENVIRONMENT ON CLOSENESS

Parents depended on the NICU staff to enable them to be involved in the care of their baby. From knowing about their child's wellbeing to the 'when and how' of spending time with them in the unit, they completely relied on the staff to facilitate physical closeness with their baby. Although necessary, this dependence resulted in parents feeling insignificant and undervalued in their roles (66, 68, 71, 72). Even though parents acknowledged their dependence on staff and the need for their support to be close to their baby, it was important for them to feel recognised as parents of the baby. They needed to feel like a significant part of their baby's life and not receiving that acknowledgement was unsettling for some(68, 71).

> *"For a long time it felt like we had borrowed a child. Not all the nurses made an effort to underline that the child really was ours"* (Mother)(71)

Fathers were often occupied with administrative tasks such as *caring of baby's siblings* or *speaking to employers*, which impacted on their ability to spend time in the NICU(66). Therefore, mothers often relied on staff to offer an opportunity for them to be involved in the baby's care(66). Moreover, structurally the hospital setup was not very 'woman friendly'. For mothers who were recovering after a difficult birth, it often felt like *being left* behind(68). It was

often a painful effort for them to get to the NICU and spend time with their baby. It multiplied their helplessness and dependency on staff to facilitate closeness with their baby(66, 68).

> *"It would have been nice if I was closer [to NICU]. I was recovering from the section and 3 hours and a long corridor away from him. It took 5 mins to get to him but the longest 5 mins of my life."* (Mother)(68)

Mothers shared fleeting instances of kindness where staff encouraged and went out of their way to facilitate physical closeness and bonding between them and their baby in NICU. Those who experienced these moments, shared them with great fondness and gratitude(66).

> *"To the NICU in bed? This can't be possible. But they [staff] said: you must see your baby, and took me there in my bed."* (Mother)(66).

2.2.3.1.4 CARING FOR THEIR BABY AROUND THE TIME OF DEATH

Overall, in this synthesis, the parents valued the experience of holding their baby and physically caring for them at the time of their death. Even though it was traumatic, in most cases parents preferred being present and were involved in the dying process(66, 68, 72, 73, 75). Seeing the transition between life and death was important for some parents to come to terms with their baby's death. For some of the parents, being with their baby after death was a need that varied from a few hours to days(66). Others took this opportunity to hold them close, talk and sing to them, wash, and dress them; tasks of a parent which they never got to perform during their child's life. Most importantly, experiencing the physical touch of their baby, having them held against their skin, not only affected their coping but also gave them solace and comfort that their child did not die alone(68, 74, 75).

> *"I held her, I talked to her.. I told her I loved her, and that [her twin sister] was waiting on her. I told her to keep an eye on her sister and to stay with her and to watch over Mommy, Daddy and her sisters. I sang to her, and held her softly, she was in pain but*

she also needed cuddled. She wiggled around and snuggled up, she opened her eyes and looked up at me. I told her that Mommy loved her and it was OK to go to sleep, and so she did. She died in my arms". (Mother)(74)

"The day Irma will be taken from the respirator to die, the parents and some close relatives visit her. The mother is in a wheelchair because she has collapsed due to stress and a bad case of the flu. Around midday the father can finally 'kangaroo' [skin to skin] *with his child. Previously he had no opportunity to do it as every time he planned to do so, Irma's condition deteriorated. Now he kangaroos with Irma while she is still attached to the respirator. The father and the mother sit on the ward; nurses have put shields around them to provide privacy and to protect other parents from seeing this sad moment…After 1h the nurse gives Irma sleeping medication and together with the neonatologist, removes the tube. They hand Irma to the mother and the parents take her to a special room where they can be alone with her…After 2 h she dies."* (Excerpt from an ethnographic study)(75)

While most parents preferred and cherished closeness, for some it was traumatising to see their baby die. Some shared graphic descriptions of the horrendous experience they had to live through and how it was etched in their memories forever(73).

"When she was struggling (to breathe) that was the worst bit…the noise she was making it was like you were killing her or something—a horrible noise." (Father)(73).

Overall, parents appreciated being given the choice regarding involvement around the time of baby's death. Some parents were afraid or unsure if they could be present with their dying baby. With some help from the staff, some parents overcame the hesitation of being with their baby around the time of death and were grateful(66-68, 71-75).

"We wanted to leave but then a night nurse asked if we didn't want to dress her, which I'm really glad about. I then said no because I was afraid to hurt something like her

little arm. She [nurse] then said that parents are usually doing this. And I was glad about that. Now, in retrospect: If she hadn't said this, we would simply have left." (Mother)(66).

Some parents experienced cultural prohibition when it came to spending time or holding their dying/deceased baby(69, 75). Some mothers reported not being allowed the choice of being with their baby after their death or participating in their funeral and burial. Being denied this opportunity, left mothers with tremendous remorse of not advocating for themselves but also immense sorrow of not being able to bid farewell to their baby(69).

"I wish I saw him before burial. I feel very sad that I didn't see him and hold him". (Mother)(69).

2.2.3.2 THEME 2- EMPOWERING OR PATERNALISTIC: SHARED DECISION-MAKING REGARDING WITHDRAWAL OF LIFE-SUSTAINING TREATMENT

The second theme of this metasynthesis is about the decision-making process of withdrawal or continuation of LST and engages with its complex nature in the parent-staff dynamic. Parents wanted to be involved and to be a central part of the decision-making process. However, they found themselves battling emotional trauma, dilemmas of decision-making, consequences, and guilt. NICU staff played a key role as parents tried to navigate through the difficult decisions and choices. Staff presented this process to parents as a shared undertaking, but it was not always an equivalent undertaking in nature. An experience that was meant to be empowering for parents during the most distressing period of their life, often ended up being a paternalistic relationship between staff and parents.

2.2.3.2.1 PARENTAL CHOICE OF INVOLVEMENT

Overall, parents were keen that everything was done for the survival of their babies in the NICU. They were willing to go to any extent and give their child a chance at life, rather than withdraw their life support and care. Parents opted or agreed to the withdrawal of LST

occasionally when they believed that aggressive intervention was causing a lot of suffering to the baby with minimal signs of any improvement. However, the general sentiment shared by parents across the relevant studies was to strive for their baby's survival, irrespective of the consequences. They were unhappy if the staff showed any hesitation towards continuing treatment for their baby, and it impacted on the parent-staff relationship negatively(72-81). For instance, in one of the studies, a mother shared how despite her insistence on doing everything possible for her baby, appropriate care was not provided by the NICU staff, "*It seemed like when they, they took her to the table to try, they put mask on her and they handed her back*."(79).

Being involved in decision-making regarding their child's treatment decisions was a core concern for parents. It was important for them to feel seen, involved and centrally considered in all aspects of decision-making. Despite being the most difficult situation for them as parents, they appreciated when staff made them feel well-informed, listened to and respected in the decision-making process. Whether their decision concerned continuing active treatment or withdrawal of LST, it was important for parents to be a significant participant as it involved the future of their child as well as their own(72-81).

> *"We are her parents, and we should make this decision. And we should decide what is best for our baby."* (Mother)(77).

Parents acknowledged their dependency on NICU staff to understand their baby's prognosis as well as to navigate decision-making, especially due to the stressful nature of the situation. To address this, it was critical that they received honest and consistent information in simple and uncomplicated language, without medical jargon. They valued doctors and nurses giving them space and an opportunity to ask questions and not feel like they were being a burden on staff (76-78, 80). With adequate information, few parents felt that they could be confident about such decision-making and as a parent in one of the studies described, *"if I could do this, I could do anything"(78).*

Few parents also saw the potential of guilt and self-blame if they had the complete responsibility of decision-making. However, it was still important for them to be involved and not just informed(76, 77, 80).

> *"As a mother I would rather be spared that (guilt). But I would really want to be well-informed and participate in the process."* (Mother)(76).

Some parents emphasised the importance of good and personalised communication but also understood the criticality of situation and dearth of time. They appreciated if they were allowed the opportunity to make sense of the demands of their situation and not be forced to arrive at conclusions(74, 76, 81). Those who experienced the urgency of situation and feeling pressurised by the NICU staff shared unpleasant anecdotes(81).

> *"The doctors kept on asking us about withdrawing care. We felt pressured to decide, almost hounded, to take Sam off life-support. It was as if they thought that we did not get it."* (Parent)(81)

It was important for parents to feel respected and acknowledged as parents of the baby. Parents appreciated kindness from staff and opportunities to discuss their concerns. Regardless of whether they were really in control, they felt involved in decision-making when they had a feeling of control, as well as the choice and agency to exercise that control(72-81).

> *"She [the doctor] said, 'you know, it is your decision. I can [make] you recommendations. We will do whatever you want to do. We can support him, take him off the ventilator"[horizontal ellipsis] I think we felt like we had complete control. So much [is] out of control that, to at least feel like you can carry out your last wishes to the best of your ability for your child is very comforting"* (Mother)(72)

2.2.3.2.2 PARENTAL STATE OF MIND

Decision-making with regards to withdrawal or continuation of care for the baby was experienced as an unimaginable emotional upheaval. It was distressing and felt to be

overwhelming for parents as they accumulated all the information thrown at them. They experienced shock, dissociation, and a form of existential crisis, as they found themselves traversing through the traumas and consequences of the decision-making(72, 74-78, 81).

> *"I so to speak just watched as if I was not involved…the entire time, I was personally affected but I did not experience it that way. It was like watching a movie. I was not really aware, and I could not really perceive the situation."* (Mother)(77).

Parents described not being able to comprehend the situation in its entirety, due to their emotional and mental state. Once comprehension was achieved, parents struggled to accept the prognosis and the truth of their baby's condition(72, 78).

> *"You know how sick he is, but your mind won't let you know how really sick he is and when the doctor said that, [you could take him off the ventilator] it was like all of a sudden, it became reality."* (Parent) (72)

Most of the parents found themselves struggling with uncertainty and experiencing decisional conflict. They often sought support in spirituality, in their spouses, family members, relatives and friends. It was traumatic for them to see their child in pain and suffering. However, they could not fathom making a decision that would end his/her life. They found themselves struggling to decide the impossible; whether to cause their child suffering or to let them go. (74, 78, 79, 81, 82).

> *"The choices were that we could keep her on the ventilator without giving her dexamethasone knowing she was going to deteriorate slowly; that we could give her the dexamethasone and see where that takes us; or, that we could withdraw treatment. The first was not a decision for us. We did not want her to suffer. We so wanted to help her, but at what cost? I remember taking a walk with my husband after talking with the doctors. We talked about quality of life. We knew that while the dexamethasone could be good for her lungs, it could be bad for her brain. We talked about what we were prepared to live with. We knew that if she was severely disabled that we would be*

unable to handle that. We did not want that for our child. We talked about what we knew and what we didn't know—the uncertainty of it all. It really felt like there was no clear right answer. And we felt like we did not have time, there was no time to make a clear decision. Time was pressing; we almost decided to withdraw treatment. But we really did not want to let her go. Perhaps we were kind of looking for an excuse to give her the dexamethasone. As we were walking back, still unsure, my husband brought up, well, what about if we ask for a head ultrasound to confirm that she does not have a brain bleed? 'Cause if she had had a brain bleed, we were not going to go on with it, 'cause then we would know that there was brain injury. So we said if there is no brain bleed, we will go ahead with it. We felt that this would be a way out of having to decide". (Parent)(81).

2.2.3.2.3 COLLABORATIVE DECISION-MAKING: RECOMMENDATIONS VERSUS OPTIONS

Parents often did not feel they were actively involved in decision-making and shared how they felt everything was already decided before it was communicated to them(77, 83). Clinicians often presented a robust and united team decision which was presented to parents as the one in the 'best interests of the baby'(76, 80, 83).

"As one of the ethnographic studies from a French NICU noted*, their uncertainty is not conveyed to parents. Instead, they would call for specific, staff-only meetings to decide any treatment limitations in these cases. These meetings, to which parents are never invited, are not really made to discuss the ambiguity per se, but are intended to create a kind of intra-professional unanimity, making prognosis a group process and building a definitive and certain answer to problematic situations; they have a more symbolic value in making all the clinicians part of* it."(80)

Choices were presented to parents as recommendations, without any alternatives or scope for disagreement. Additionally, since most parents relied heavily on staff for support and

guidance, they were often left with no choice but to accept the recommendations provided to them(72, 74, 75, 81, 83). As a mother mentioned, '*it doesn't look like I have an option'*(83).

> *"The doctors make strong suggestions so that you cannot really decide. you do what the hospital offers you. A different hospital might act differently. possibly there were other options, but when you do not know what other options there are, how should you decide?".* (Father)(77).

Such communication often left parents perplexed and in a dilemma. There was dissatisfaction among parents with the way options and recommendations were communicated to them(74, 83). They found them to be prejudiced and often directive. One mother shared their clinician's remark, ''*If he were my child, I'd take him off the respirator,"*(74). Parents insinuated that the discussions were held to make it seem like an inclusive endeavour, whereas in reality, the decision had already been made.

> *"I felt that we were seemingly being included, but that they wanted us to agree with them. I did not feel that the decision was being taken over our heads. It seemed to me as though they hoped that we would to some extent agree, so that we would not stand against them, so we were not completely opposed to them".* (Mother 20)(76).

On the contrary, parents appreciated it if staff approached them with humility, acknowledged the uncertainty and allowed them the choice of decision. A trusting relationship was important. It brought them closer to staff and allowed a more reciprocating dynamic as all efforts were intended towards finding the best possible direction(72, 74, 76, 77, 79).

> *"I think, if one (the doctor) can convey the reality that we are not God, in the sense that we don't have control over things. The doctor had limitations and she wasn't trying to be something more than she could be. She humbled herself*." (Parent) (72)

2.2.3.3 THEME 3- COMPASSIONATE CARE: PARENTS' NEEDS FROM COMMUNICATION WITH STAFF

As parents dealt with uncertainty, trauma, and fear of outcomes, they looked for compassion and respectful engagement with staff. An absence of these often affected their experiences in an inherently challenging NICU environment. In the final theme of this metasynthesis I explore compassionate care as a key tenet for parent centred NICU setting.

2.2.3.3.1 UNDERSTANDING PARENT'S NEEDS

All parents, but especially mothers, needed more compassionate care from NICU staff. They expected greater empathy than what had been shown to them and more understanding regarding their complex situation. Mothers were more explicit in expressing how often staff were inconsiderate in acknowledging their physical and emotional condition, after a difficult birth and separation from their newborn baby (66, 70, 78, 82, 84, 85). One of the mothers said:

> *"They just have to let you know every step of the way and be compassionate about it. Because, don't, don't be harsh about it. You've gotta—you gotta be empathetic with the parents because it's, it's scary laying here and you are carrying a baby all these months and you want the best for it and then one day it's just up and coming out and you don't know why."* (Mother) (78)

It was important for mothers that efforts were made by staff to understand what their needs were, rather than exercising control by telling them what they are '*allowed*' to do(68).

> *"When parents want to go to NICU after having a baby they should be able to, not convinced to stay on ward or be told to wait for wheelchair for 4 hours."* (Mother)(68)

Parents felt they were cared for when their needs were prioritised over standardised procedures and hospital regulations. They also believed that staff could address their needs by having empathetic communication and being receptive to their individual needs. Not

receiving this support led to mothers feeling frustrated and abandoned(66, 68, 70, 72, 77, 82, 84, 85).

> "One of the mothers said, "*For instance they [nurses and physicians] did not answer me appropriately, I would like they speak with me more accurately, but they did not take the time to answer my questions, though I was in a bad emotional state, I expected they become more patient, and nurses have more compassion with me".* (Mother) (82)

2.2.3.3.2 COMMUNICATION WITH STAFF

Communication in the NICU has been a core tenet of parental experiences in the included studies. Honest and respectful communication was a key component of positive NICU experience, despite bereavement. Parents stressed the importance of honest and direct communication. They needed adequate information in a non-medicalised manner. While it was important that staff tried to understand what level of details parents needed, it was critical that information was not concealed from them. Lack of good communication was experienced as lack of good support (66, 67, 70, 71, 76, 77, 79).

> *"It was very important for us to get some time with these very busy doctors. I think that on certain occasions the doctors should perhaps take the initiative to work out an agreement with parents such as shall I bother you with all the details that worry me, or shall I not say anything, or shall we try to find a good middle ground about what I tell you? I had more than enough problems without having to worry about all the things that could go wrong".* (Parent)(76)

> *"Well yeah, for instance they (nurses and physicians) did not answer me appropriately, I would like they speak with me more accurately, but they did not take the time to answer my questions, though I was in a bad emotional state, I expected they become more patient, and nurses have more compassion with me". (Mother)(82)*

There were instances of disrespectful communication due to staff's lack of understanding of parents' needs. Terms such as "*expire*" or "*developmentally delayed"* were used with reference to the babies(74), which parents found very distressing. Even though retrospectively they seem to realise that staff were trying to prepare parents for the worst possible scenarios, it was felt to be inconsiderate of their feelings(70, 74).

> "*They must mind their words. They should talk differently. They should mind what they should say and should not say."* (Mother)(70)

Parents appreciated when staff communicated in gestures such as subtle physical contact, expressing emotions, and showcasing their *human side*(72, 77).

> *"It is not necessarily important to see someone weep over my child, per se, but it is helpful, and it is just immensely valuable to have them express genuine emotions. It provides an atmosphere that it makes it easier to make these difficult decisions when you feel like you are in an atmosphere of people who are supportive and caring and sensitive".* (Parent)(72).

2.2.3.3.3 CONTINUITY AND CONSISTENCY

Structural challenges, such as lack of continuity of staff impacted on the experiences of parents negatively. As described by a mother in one of the studies, "*I have certainly experienced many times that people [nurses] have asked, 'is this your first child?'. Try reading our record! But it became very clear that the longer we were admitted to the NICU, the further back the new nurses had to read to realise that he had had a twin"*(71).

Parents repeatedly stressed the importance of consistent communication, which was often absent due to frequent shift changes, further exacerbating their anxieties. It affected their relationship and trust with the staff, especially as parents would develop confidential rapport with nurses who spent more time with them and the babies. They preferred obtaining

information from a limited number of staff in order to avoid receiving conflicting information(68, 71, 77, 78).

> *"Care from the Nurses was very variable. Some were great—very competent and good at explaining what they were doing to anxious parents. But others were rushed, seemed stressed and made us feel as if we were not welcome, and this upset us as we didn't want to make things any worse, but we also really wanted to spend time with our little baby daughter. The advice on when to do comfort holding etc varied from person to person—it would have been better if we'd had consistent advice"*. (Mother)(68).

2.2.4 LINE-OF-ARGUMENT SYNTHESIS

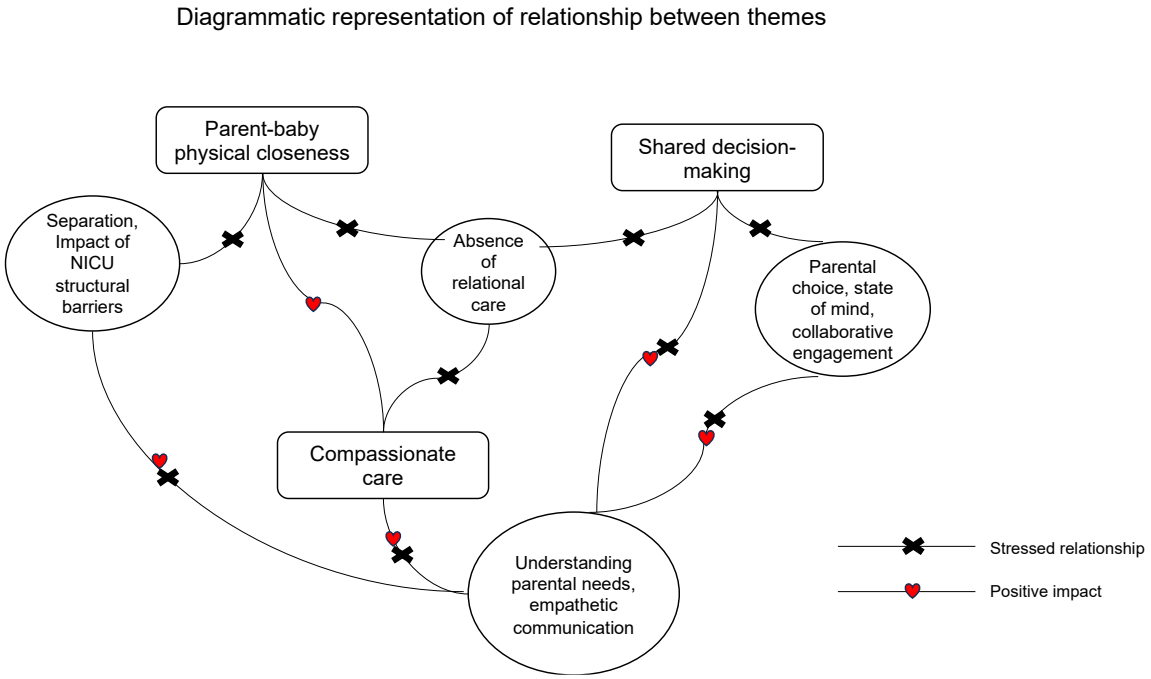
Absence of relational care in the NICU impacts on parent's grief and bereavement experience. As suggested by the present metasynthesis, each parent in the NICU has their own distinct and contextual needs and while it may be challenging for staff to provide tailored personalised care in a medically demanding environment, it is the key to a positive NICU experience. Underlying power imbalances and fragmented communication were evident within the findings. These relationships, structural factors and communication affected the staff-parent dynamic. Moreover, the power differential manifested in various ways; for instance, the manner of information sharing with parents, controlled and regulated access to the baby or limited parental autonomy in decision-making.

2.2.5 RELATIONSHIP BETWEEN THEMES

The NICU period started with a traumatic separation of parents from their baby. At this stage, the NICU staff played a key role in facilitating physical and emotional closeness of parents and the baby. In addition to the early separation, unexpected and disrupted parental roles as well as structural barriers of the NICU affected parental stress and anticipatory grief. Understanding parent's needs and addressing them with empathy helps build a trusting

relationship between parents and staff. Further along as baby's condition worsened, the process of decision-making was initiated, with parents and staff sharing information about prognosis and treatment options. This communication depended on the relationship and rapport established between parents and staff and was often complicated by the paternalistic recommendations made by the clinical team. This situation was marked by an absence of relational care with a perceived lack of empathy and understanding of parental needs. Parents, especially mothers, felt abandoned and found themselves with an absolute lack of control and choice. It is important to note that this situation can often be overturned with compassionate and respectful communication which affects parent's trust in the staff. The level of trust in turn affected the integration and evaluation of information. The process of decision-making was facilitated by exchange of information and communication between parents and staff.

Figure 2- Relationship between themes



2.3 DISCUSSION

These data, to the best of my knowledge, are the first meta-synthesis of the published qualitative literature for building an understanding of overall parental experiences of newborn

death. Building on the critical re-interpretations of selected studies, I have presented a comprehensive insight of being a parent in the NICU and experiencing bereavement. These understandings generated from the three core themes point towards the underlying reality of parental needs of physical closeness, of the complex processes of decision-making as well as the role of compassionate care in the NICU. In the following paragraphs, I will discuss the three core themes, critically analyse the published literature, understand the consistencies as well as new knowledge contributed by this review.

The first theme is about the importance and need for physical contact between the parents and baby in the NICU. Touching or holding the baby, skin-to-skin contact between parents and baby, talking to the baby and spending time are believed to be essential for parents to bond with their infants and feel the love for them(86-88). A metasynthesis exploring parent's experiences of emotional closeness with their infants in the NICU suggested a more planned effort for utilising NICU resources and interactions between parents, staff and other family members to facilitate, as well as promote parent-infant closeness(89). While it may be challenging to pursue skin-to-skin in extremely sick and ventilated babies, the need for closeness in NICU has been well established as important in promoting bonding and wellness of both parents and the baby. However, there is a gap in extending this recognition as the baby transitions from being alive to their subsequent death. Few studies acknowledge the impact of being present around the time of death in parent's sense of self and long-term grief(68, 90). In stillbirth, it was recognised that giving an informed choice to parents to see and hold their stillborn baby was important for their grief and future well-being(91-93). The insights offered by this metasynthesis bring in a new perspective to recognise and facilitate the transcendental needs of parents for physical and emotional closeness with their baby.

The second theme is about shared decision-making in NICU. This became a popular idea in the early 1990s(94) as a process in healthcare to encourage active involvement of patients in decisions concerning them and their health. A move from the autocratic style of clinical decision-making to a participatory model was deemed necessary in order to promote patient-

centred care(94). A similar shift has been underway in neonatal intensive care, with frameworks developed by professional associations like the Royal College of Paediatrics and Child Health(5) (RCPCH) and British Association of Perinatal Medicine(6) (BAPM) recommending a focus on the child's best interests, requiring considerations beyond clinical context to that of the family's situation in its entirety. A shared decision making model dominates the policy and practice guidelines(7). However, as this metasynthesis highlights, the reality is often far from ideal, where an absence of relational and personalised care creates a misalignment between staff and parents leading to a soured experience for all involved. Perhaps, a well-intentioned but paternalistic endeavour to protect parents from guilt and suffering, sometimes results in a withdrawal of parental autonomy and staff-parent conflicts. Other studies have also shown how parental involvement can be restricted due to 'minimal psychosocial' conversations and amplified power imbalances between staff and parents, and inadequate information sharing(95-97). Moreover, while clinicians may be following recommendations of practice, the usage of the term 'recommendations', has been shown to cause resistance (96, 98).

Finally, the third theme brings to our attention the role of compassionate care in NICU. Issues related to empathetic and respectful communication have been previously identified in the literature. The findings of this metasynthesis align with some of the previously published literature confirming that communication in NICU is often the main predictor and defining factor of perceived quality of care by parents(99). Another review acknowledged the unique skill-set required from the NICU staff, as they carry a double responsibility of caring for sick babies as well as distressed parents, requiring more emphasis on tailored communication (100). However, while the importance of individualised communication has been recognised, the underlying phenomenon of compassionate care as a core value in NICU remains relatively under-explored.

2.3.1 LIMITATIONS

This metasynthesis has a number of limitations. First, the cut-off period of study within two years of newborn death restricted the inclusion of some relevant studies, that looked on parental experiences around the time of newborn death. The cut-off period was initially implemented throughout the doctoral project due to a perceived impact of time since bereavement on the recall of NICU experiences by parents. However, as the study progressed the advisory group comprising of bereaved parents (Patient and Public Involvement or PPI) suggested that parents with a longer bereavement period from the empirical study must not be excluded from the study. As a result, the criteria were changed for primary data collection (further explained in section 3.2.2), but remained for the purposes of this metasynthesis.

Secondly, although there was some representation of ethnically diverse communities, most of the studies were from high-income settings, lacking representation from low-middle income countries. This is also reflective of wider published evidence. Although majority (98%) of stillbirths and newborn deaths occur in low-middle income countries(101), for long perinatal grief was considered as a western phenomenon(102), neglecting the experiences of parents from these settings.

Thirdly, details on methods and analysis were inconsistently presented in the studies, making it difficult to evaluate thoroughly and comment on the study designs and quality.

More importantly, all the studies in this synthesis had varying objectives and research questions related to specific aspects of newborn death and bereavement. None of the studies to date have reported the holistic experience of parents in the NICU. Out of the 20 studies included in this review, 12 were focussed on withdrawal of LST and decision-making in the NICU, which is reflective of the general research priorities. Other studies looked at various aspects of newborn deaths, including parental experiences of pre-term deaths, spirituality and memory making. Five studies explored the overall experiences of newborn death, out of which 3 focussed on maternal experiences, excluding the voices of fathers. Although, some of the

previously conducted metasynthesis and reviews have looked at general NICU experiences of parents (non-death related) (103, 104), ethical decision-making in the NICU(97, 105-107), parental grief (108, 109) bereavement support interventions(110-112) etc., this review is the first one to synthesise comprehensively the parental experiences of newborn death.

2.4 CONCLUSION

In this review I have explored, synthesised, and interpreted the reports of parents' experience of newborn death in the NICU. Thematic analysis revealed three key themes: 1) Transcending life and death: parents' need for physical closeness, 2) Empowering or paternalistic: shared decision-making regarding withdrawal of life-sustaining treatment and 3) Compassionate care: parents' needs from communication with staff. With this I was able to explore parental experiences of newborn death through a wider lens, as a whole, and explore the inter-relatedness of these individual aspects. While each study had its own focus, it provided me with an overarching view of parental experiences from varied backgrounds. The comprehensive approach allowed me to explore commonalities and diversities in experiences of parents and develop a nuanced interpretation of the impact of lack of relational care on parental experiences. Further, this gap in the literature allowed me to reflect and reinforce the need for conducting a comprehensive empirical study exploring the in-depth lived experiences of parents bereaved from newborn death in the NHS.

CHAPTER THREE- RESEARCH METHODOLGOY, METHODS AND DESIGN

3.0 INTRODUCTION

This chapter is divided into two sections. The first section discusses the conceptual and theoretical underpinnings of the study. This will include some of the key concepts of the theoretical framework relevant to the study and outline the selection of the methodology. A qualitative paradigm was chosen as appropriate to the exploratory nature of this research study and its focus on lived experience. A hermeneutic phenomenological approach was deemed as the appropriate methodology for this study to explore and understand the lived experiences of newborn death from parent's and staff's perspective, which will be discussed in greater detail throughout the section.

The second section explores the overall research design, methods, and analytic approach. It will also discuss the study's ethical considerations, governance, and rigour.

3.1 SECTION ONE

3.1.1 RESEARCH PARADIGM

To undertake any research, the researcher must be aware of the influences on them and their paradigmatic stance. According to Thomas Kuhn (1970), who first defined and explained the concept, a paradigm is a particular range of beliefs and values that contribute to the way of seeing the world for a particular discipline(113). Patton defined a paradigm as "*a world view,*

a general perspective, a way of breaking down the complexity of the real world"(114)(p.37). It is a belief or a school of thought that guides the researcher in the acquisition of knowledge(115). There are two main paradigms currently operating in the field of healthcare research- positivism and interpretivism. Guba and Lincoln(116) identified three assumptions that help understand a paradigm; 1) the ontological (nature of social reality of the study of being), the epistemological (nature of knowledge or how we understand the world), and the methodology (how to obtain the desired knowledge). For the purpose of this thesis, I intend to clarify my standpoint within these terminologies by outlining the two major paradigms.

3.1.1.1 POSITIVISM

The positivist paradigm adopts a realist ontology, knowing the world from an objective observation, driven by natural laws and independent of human beings. Objectivism is the search for a truth that already exists. Those working within the positivist approach are committed to following an objectivist epistemology and understanding the nature of the empirical world from a distance, to avoid researcher's bias(117). The positivist paradigm frequently works within a quantitative frame of reference consistent with the idea that reality is fixed and orderly, can be objectively measured, and subject to experimental investigations (115).

3.1.1.2 INTERPRETIVISM

In contrast to positivism, the interpretivist paradigm suggests that the objectivist assumptions may be appropriate for understanding the physical world, but not for the study of the social world and human experiences. Interpretivism, asserts that multiple realities exist that are socially constructed, influenced by history and culture. Meaning is constructed because of one's being in the world and therefore, since for any inquiry many interpretations can be made, interpretivism adopts a relativist ontology(118). Recognising the relative nature of understanding, interpretivism adopts a subjective epistemology and often uses qualitative methodologies to understand individual constructions of the world(119).

For the purposes of this study, its focus on human experience and exploratory nature, the theoretical perspective adopted was interpretivism, which informs phenomenology as well as hermeneutics. The hermeneutic phenomenological ideas of Heidegger and Gadamer are particularly consistent with the interpretivist tradition.

3.1.2 PHENOMENOLOGY

Phenomenology offers an approach to understand unique individuals, and interactions with others and the environment. It is both a philosophical movement and a research methodology, whereby the aim is to explore the human experience (phenomena) as it is lived, rather than how it is conceptualised or theorised. For any qualitative research it is important to establish linkage between the methodology and philosophical underpinnings that guide the method(120). Not doing so, brings in a risk of introducing ambiguity in its purpose, structure, rigour, and findings. Phenomenology was deemed as the most suitable underlying philosophy associated with the exploratory nature of the study. However, there is more than one philosophical school of phenomenology and in the following sub-sections I will discuss the two main approaches, descriptive and interpretive phenomenology.

3.1.2.1 HUSSERL'S DESCRIPTIVE PHENOMENOLOGY

Commonly held as the founder of phenomenology(121), Edmund Husserl's philosophical ideas gave rise to the branch of descriptive phenomenology(122). The core assumption in Husserl's philosophy was that human experience as perceived by our consciousness has great value and therefore must be an object of scientific enquiry itself. He was interested in the essential structure of human experience that can be described. 'Lifeworld' is a key concept in Husserl's philosophy. It consists of objects that we are conscious of, and by being conscious it means they are important to us(123). This is the concept of intentionality, which refers to an internal human experience of being conscious of an object and therefore directing our thoughts towards it. Lifeworld is this experience, which is understood pre-reflectively(124).

A key tenet of Husserlian phenomenology is the principle that it is important for the researcher to shed all prior knowledge and pre-conceived notions and biases to grasp the essence of the lived experience being studied. In order to gain essential understanding, the researcher performs transcendental phenomenological reduction, which is commonly known in phenomenology as "*bracketing*". Husserl describes bracketing as "*refraining from judgement*"(123) (p.109). This means that the researcher must consciously strip themselves of all expert knowledge as well as notions from personal experiences(125). The aim of the researcher is to achieve transcendental subjectivity, a Husserlian concept, which further ensures the validity or objectivity of the interpretation against the biased perspective of the researcher(121).

3.1.2.2 HEIDEGGER'S INTERPRETIVE PHENOMENOLOGY

Phenomenology was advanced by Martin Heidegger, a student of Husserl, in a different way. He challenged some of Husserl's assumptions on how phenomenology could guide meaningful inquiry with description alone. He was more concerned with understanding those experiences and adopted an ontological approach of "*what does it mean to be a person*?"(126) (p.42), as against the transcendental approach of Husserl. In this respect, Heidegger's ideas embraced the interpretive and hermeneutic nature of research(122).

Heidegger was interested in "Being", which he noted is the "the most universal and emptiest of concepts"(127). To understand the "Being" is to understand the meaning of that phenomenon(128). Heidegger was interested in *Dasein* ("Being there") and specifically what it means to be in the world, *Being-in-the-world* (p.33), because he believed that humans cannot disassociate themselves for the world(127). In terms of study of human experiences, Heidegger's phenomenology goes beyond the mere description of concepts and experiences. As quoted by Manen, "*the lifeworld, the world of lived experience, is both the source and object of phenomenological research... the starting point and end point*"(128) (p. 36). It strives to look for meanings embedded in the 'everydayness' of these lived experiences and how these

meanings may influence the choices made(126). It tries to explore the lifeworld ontologically by trying to 'recover' a deeper meaning of everyday experiences(128). These meanings may not always be apparent to the individual themselves, but can be garnered from the rich narratives they produce. Therefore, the focus of a hermeneutic inquiry is not what humans know, but what they experience and the interpretation of that experience(129). It is interested in what those everyday lived experiences those human narratives bring with them(129), while *Being-in-the-world*(127).

An important philosophical assumption underlying the phenomenology of Heidegger is the importance of expert knowledge or presuppositions. He emphasised that it is not possible for the researcher to clear their mind completely of their understandings and background that originally led them to the topic of interest(121). Heidegger rejected the concept of bracketing and believed that researcher's pre-conceived notions and personal experiences are essential to understanding and interpretation of meaning(130). For Heidegger. the term lifeworld was to express the sense that realities of individuals are invariably influenced by the world in which they live. He recognised the temporality of human beings and their embeddedness in history, culture, and traditions. Therefore, understanding and interpretation is based on individual's 'fore-having, fore-sight and fore-conception'(127).

Another key concept proposed by Heidegger was that of constitutionality, which articulates the idea that interpretative meanings emerging from the research are a blend of meanings articulated by the researcher and the participant in the process of the study(121). Gadamer explained this constitutionality of intersubjectivity as "fusion of horizons"(131). He included assumptions, ideas, meanings as well as personal experiences in horizon, which are fluid in nature and dependent on their situatedness in time. Any interaction between two individuals is based on personal horizon of experiences and meaning, and the resulting interpretation is dependent on the intersection of these horizons of the researcher and the participant(130). This subjectivity means that there could be more than one interpretation of narrative. Therefore, in hermeneutic phenomenology there may not be a one true meaning, but rather

the meanings that are emerging from the interpretive research must be logical and plausible within the study framework, reflecting realities of the participant's lived experiences(132). The researcher must interpret the findings to produce meanings for practice, education and research to contribute towards informed and culturally sensitive healthcare knowledge(133).

Heidegger brought an interpretive lens to phenomenology, where humans need to interpret to understand, and therefore was unsatisfied with description by itself(127). To achieve interpretation Heidegger used the hermeneutic circle, the "*circle of understanding*"(127) (p.195), where interpretation is seen as a circular process. Prior to engaging with this circle, the researchers' fore-structures of understanding must be made explicit, as challenging them aids the process of interpretation while considering the phenomena. As Gadamer said, it is important the researcher to maintain focus on the phenomena of interest and not become distracted by their fore-structures(134). In the hermeneutic circle, interpretation is seen as a circular process, where the parts of narrative are considered in terms of the whole of the understanding and then considered in new ways(135). There have been different standpoints with regards to the circle(136). It has been described as the process of interpreting parts of the text in relation to the whole(130) and vice-a-versa, and others have seen it as a sharing of culture and language between the researcher and their participants(126). However, Gadamer did not agree with the formal and simplified methodological understanding of the circle but suggested the role of ontological state in understanding(134).

3.1.2.3 ISSUES AND ARGUMENTS RELATING TO THE USE OF HERMENEUTIC PHENOMENOLOGY

A phenomenological stance is primarily a philosophical stance. To use phenomenology in research, several methodological interpretations and approaches have emerged over the years. However, there are many criticisms of the suitability of these methodologies(136-138), especially to the apparent lack of grasp of the theoretical underpinnings and criticisms of

application. In this section I will briefly summarise the prominent issues that have been raised around the use of phenomenology and hermeneutics in research.

One of the biggest criticisms of researchers using phenomenology has been their failure to understand the philosophy, which has led to a mix of methods being applied (136, 138). Lack of adequate understanding of the philosophical underpinnings also translates to a failure in describing the school of thought being followed, i.e. whether descriptive or interpretive phenomenology(138). The foundational principles on which a particular research study is based need to be clarified at the outset and it is important to ensure that the philosophical school has been followed consistently through the life of the research in question(136).

Another common issue that surfaces with hermeneutic phenomenology is the failure of researchers to explore the phenomena in enough depth. Researchers have been criticised for misinterpreting the subjectivity of the methodology and limiting their quest for understanding the lived experience from the perspective of the participant(136, 138, 139). What is then missed, is capturing, and exploring the essence of the phenomena. It is important for researchers to understand that while the lived experience of the individual is a key factor, it is the description and interpretation of the phenomena that must be the singular focus for the research.

Finally, there have been arguments surrounding the analytical frameworks corresponding with hermeneutic phenomenology. Todres(140), Giorgi(141, 142), Colaizzi(143) and Van Kamm (144) describe different methods of analysis, with specifically prescribed steps in their approach. However, some of these approaches, such as ones suggested by Giorgi(142), Van Kamm(144) and Colaizzi(143) have been associated with Husserlian philosophy but have also been used by those following Heidegger's school of thought. It has been argued that structured approaches are contrary to Heidegger's interpretive approach and not conducive with the philosophy(121). This is an important rationale as to why a formalised analytical approach was deemed unsuitable for this research study and a more reflective approach, proposed by Van

Manen(128), was adopted for exploring the essence of lived experiences of newborn death. This approach allowed me to look at the responses of parents and staff through meaning, importantly by highlighting issues that would have not been considered otherwise(128).

3.1.3 ANALYSIS: VAN MANEN'S HERMENEUTIC PHENOMENOLOGICAL REFLECTION

Hermeneutic phenomenological reflection by Van Manen was chosen to guide the analysis for this research. Manen explained that the purpose of phenomenological research is to understand the essential meaning of the lived experience(128). He argues that a lived experience must be captured in language and presented textually and that this transformation and translation from language to text is an interpretative process that the researcher undergoes to generate understanding. He agrees that while some descriptions and narratives may be richer that others, they are all individually lived experiences with something unique to offer. In order to gain insight into the essence of a phenomenon, Manen suggests that themes should be used as structures of meaning(128) and proposes three steps for doing so. First, understand the text as a whole by reading and re-reading the transcripts; second, highlight statements related to the phenomenon of newborn death and; third, use a very detailed approach by considering every sentence or a cluster of sentences to identify commonalities and themes(128). Although, Manen does not explicitly discuss it, this process is consistent with the hermeneutic circle proposed by Heidegger, who describes it as a *"circle of understanding"*, where it is impossible to understand the whole without understanding the parts(145). With the hermeneutic circle, the analysis is cyclical and dynamic, fitting well with the interpretive process suggested by Manen.

Manen argues that by isolating thematic aspects or significant statements, the researcher uncovers the meaning of the phenomenon with the analysis of the verbatim text(128). It is important here to note that although Manen describes the principles involved in analysis, it is not a formalised stepwise process that one must follow to achieve hermeneutic analysis. A

phenomenological analysis is a reflective process that does not involve coding and sorting of data to search for patterns and repetitions. It is an inquiry that proceeds through an iterative process of deeply engaging with the texts, reflective wondering and questioning, and interpreting the meanings of lived experiences; thereby letting a phenomenon reveal itself(146).

3.1.4 REFLEXIVITY

Heidegger emphasized that it is impossible to free one's mind of their background and of understandings that led them to consider a topic of research in the first place(121). Therefore, according to hermeneutic scholars personal knowledge is both necessary and useful to research(130). However, it is imperative in hermeneutic tradition that pre-conceptions are made explicit throughout the process.

Reflexivity is defined as "*the process of continually reflecting on our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings*"(147)(p.108). In qualitative research reflexivity is used as a method to increase the validity and trustworthiness of data(147, 148). Researcher reflexivity is essentially a researcher's insight into their own biases and rationale for decision-making in all aspects of study design, and is therefore critical to maintain rigor(149). Heideggerian hermeneutic phenomenology is inherently reflexive in nature, as the methodology expects researcher to acknowledge their fore-structures of understanding from the outset. Use of reflexivity in research accepts the central role played by the researcher. However, Heidegger stressed the importance of re-evaluating and acknowledging the fore-structures of understanding before entering the hermeneutic circle of understanding and continue throughout the process of interpretation. Therefore, reflexivity can be placed centrally in the conceptual understanding of hermeneutic phenomenological philosophy.

For the purposes of this study, my (evolving) fore-structures of understanding as a social scientist, a woman of colour and a mother, have been acknowledged and identified as far as possible from the outset. It was my inability to effectively “bracket” that further reinforced the suitability of this methodology. The position of reflexivity continued throughout the study period, starting right from study conception, design, data collection, analysis, and dissemination. It allowed me to understand my biases, gain more understanding of my cultural and contextual awareness and allowed me a new and more in-depth exploration into the phenomena. A reflexive journal was maintained throughout the process, that aided engagement with my own views and opinions, especially as they evolved during the study due to changes in my situatedness. Heidegger explores situatedness (*'befindlich*' in German) as something that refers to situational circumstances of *action* and *mood*(127). In this study, parents were situated in the real world (NICU) where unique experiences shaped their lifeworld. My fore-structures evolved when I became a mother (during the course of the study) and experienced the healthcare system as a ‘parent’. Therefore, having a reflexive journal allowed me to uncover and understand my situatedness and its impact on my engagement with the study. Although self-awareness is challenging, it is also the key in achieving and maintaining reflexivity in the research process(150).

3.1.5 RATIONALE FOR METHODOLOGY

Researchers in healthcare and social welfare use interpretive phenomenological research as it allows them to examine the ‘lived experience’(136). The lived experience is to understand the phenomenon from the perspective of the person experiencing it. A key objective in this study was to share intensely personal accounts of these lived experiences. It was a conscious decision to not bring a specific theoretical lens to the study, as well as not aiming to develop a theory, as in a grounded theory approach. A qualitative methodological approach appeared suitable to aid the exploration of the meaning and nature of experiences of newborn death from a parent’s and NICU staff’s perspective. Although newborn death is an event, the lived

experiences around this event are intangible and constructed through interpretation. Hence, an interpretive stance was required and necessitated a hermeneutic approach. Moreover, phenomenology attempts to understand the holistic nature of the phenomenon rather than focusing a particular aspect or concept(128, 146), and a newborn death is not an isolated event, but its impact is a life changing one. It is influenced by an individual's situatedness, their temporality as well as cultural and historical influences. In addition, I bring my own situatedness to the research, and therefore, from all aspects considered, hermeneutic phenomenology was chosen as the most appropriate philosophical stance and provided the theoretical underpinning for this research study.

3.2 SECTION TWO – STUDY DESIGN AND METHODS

This section will discuss the overall methods and design used to conduct the study. The analysis process will be discussed. A discussion of ethical considerations in relation to the study will conclude this chapter.

The aims and objectives of the study were explored in chapter one (see section1.5). They were. primarily to gain understanding of the meaning and essence of, 1) the personal experiences of parents' of newborn death in the UK, within the context of the clinical encounter, and 2) the NICU staff's experiences of newborn death and supporting grieving and bereaved parents in the NICU. The study used a retrospective qualitative research design following the interpretive school of Martin Heidegger.

3.2.1 PATIENT AND PUBLIC INVOLVEMENT

A representative group of bereaved parents (Patient and Public Involvement or PPI) from diverse ethnic background was established at the outset of the study. With help from the Imperial Patient Experience and Research Centre, an involvement strategy was developed,

and the opportunity to get involved was posted on the Imperial 'voice-global' platform, inviting advisors who had been bereaved by newborn death to form the PPI group for the study. Their contributions were invited for all stages of the study, starting from development of research design to dissemination of study findings. I also applied for the Public Involvement Fund from National Institute of Health and Care Research (NIHR)- Research Design Service London and was granted the support (see appendix 2). This grant allowed me to reimburse the time invested by PPI members in the study.

I organised preliminary meetings with the PPI members to discuss the study design. The advisors shared their experiences of bereavement and noted key distinctions among cultures. Overall, all the members were in complete support of the project as well as the methods and expressed their willingness to continue supporting the study. They agreed that a structured examination of grief would be inappropriate and supported a participant-led conversation as in phenomenology, to provide in-depth insights into how NICU environment, as well as the social and cultural backgrounds impact their grief and bereavement journey. PPI contributions to the study will be discussed across the chapter to highlight their key contributions in the study.

3.2.2 SAMPLE SIZE

In a phenomenological study, the sample is chosen to provide detailed data concerning the phenomena under investigation(151). The goal of a hermeneutic phenomenological study is not to generalise to a population, but to gain insights into a phenomenon or individuals or events. Purposive sampling is used to achieve this goal, as it allows the researcher to select those people who have experience of the phenomenon. In phenomenology, the study sample is chosen to provide in-depth data of the phenomenon under exploration(151). It has been argued that phenomenological studies do not seek to obtain data saturation, but to gather detailed and in-depth data from a small group of participants to inform and not to

generalise(151-153). The data are engaged with in intensive and comprehensive analysis(151, 154).

There are varied suggestions on sample size selection for phenomenological studies, with some authors suggesting that a minimum of three participants may be adequate(155). One of the challenges of data collection in a phenomenological study is ensuring the amount of data generated is manageable and sufficient to produce credible results(151). Manen stated that a small sample size allows in-depth data to be collected and analysed(128) and in keeping with the theoretical underpinnings of the study, a small sample size was anticipated to give rise to rich data enabling intensive analysis.

The aim was to recruit between 8-10 parents, with a maximum of 20 parents, who had experienced newborn death. The final number achieved was able to provide rich in-depth data, portraying individual accounts of parents' personal experience of the NICU and their newborn baby's death (see chapter 4). Similarly, to address the second objective of the study, a sample size of 8-10 NICU staff was planned for recruitment to the study. However, if more parents and staff had wished to narrate their experience, it would have been welcomed as some common trends that were found, might have been more pronounced if higher sample numbers had been achieved. Since, the focus of this interpretive study was not to attempt generalisation of findings; an in-depth exploration of parents' and staff's experiences of newborn death was sought.

Originally, the plan was to recruit parents who had experienced newborn death in the preceding two years before the interview. The reason for having this time restriction was my assumption that a longer time since bereavement may impact on parents' recall of the NICU experiences. However, upon discussion with the PPI group, this restriction was removed. PPI members strongly stated that bereaved parents do not forget their experiences, regardless of the time period, and the study may fail to fully understand the long-term impact of newborn death and NICU experiences, if the two years restriction was employed.

Participants were eligible to participate in the study based on the following inclusion and exclusion criteria-

Inclusion criteria

- Mothers and fathers, (from same or different families), of at least 18 years of age who held the capacity to consent, and whose baby had died in a NICU in the UK.
- Neonatal intensive care staff, including doctors and nurses who have experience of caring for newborns who are likely to die, withdrawal or withholding LST and providing support to bereaved parents in neonatal unit.

Exclusion criteria

- Parents who declined consent.
- Parents identified by clinical care team as inappropriate to include, for reasons such as extreme emotional distress, who are likely to experience negative impact of being in an in-depth interview.
- Neonatal intensive care staff who decline consent.

3.2.3 RECRUITMENT OF STUDY PARTICIPANTS

Prior to beginning the study, ethical approval was obtained from the London - Brent Research Ethics Committee (Ref: 11/H0717/6). Imperial College London was the academic host of the study and provided insurance for the study. Further permissions were sought at the three participating hospitals before the study launch and initiation of recruitment. Names of the participating hospitals are concealed to ensure anonymity of study participants. Participant Information Leaflets (PIL) and consent forms were developed in the English language and reviewed by the PPI group. This section will discuss the recruitment methods used in the study for parents and NICU staff.

3.2.3.1 RECRUITMENT OF BEREAVED PARENTS

The two methods used for parental recruitment, are described in detail below and presented diagrammatically in Figure 3.

NHS Recruitment – The three participating centres are tertiary level hospitals with level three neonatal units providing special care, high dependency care, and intensive care for a range of circumstances. The study was introduced to all neonatal staff in the participating centres using PowerPoint presentations and discussion. It was agreed that I would work closely with the NICU nurses and consultants to identify parents who would be eligible to participate in the study based on the eligibility criteria. Because of the highly sensitive nature of this research study, it was decided that the clinical care team would first approach bereaved parents at the bereavement follow-up appointment organised around 3 months after newborn's death. At this stage the clinical team would identify if parents were willing to be approached for participation in the study. Once an agreement in principle was established, a preliminary meeting was organised between me and the parents to discuss the study in detail, including the PIL and the consent form. Parents were given an opportunity to ask questions and given assurances of anonymity, confidentiality, and their right to withdraw from the study at any time. Once the written consent was obtained, a convenient time and date was finalised for the interview.

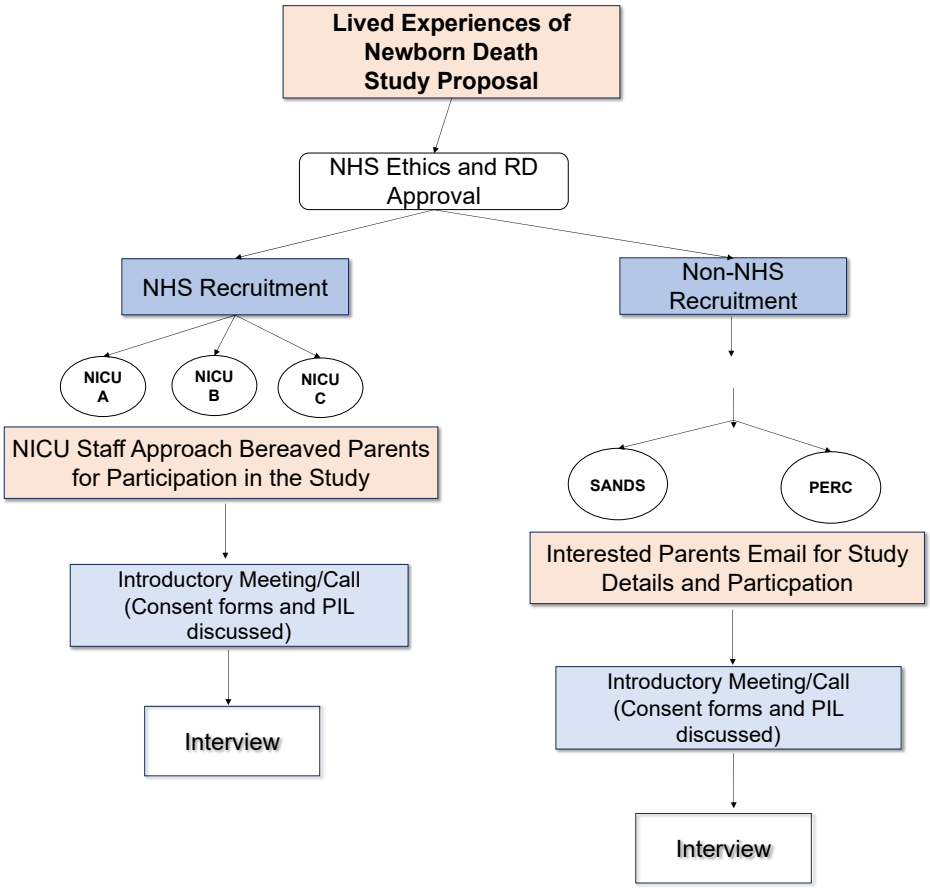
A few barriers were experienced through the NHS recruitment route. First, most of the neonatal consultants were in regular contact with bereaved parents up until their bereavement follow-up appointment held at 3 months after the newborn's death. At this stage, it was perceived that parental grief was still very raw and consultants feared it may result in causing more harm to approach parents in a study that would ask them to relive their NICU experiences. Second, it was not a common practice for NICU nurses and consultants to keep in touch with parents in the long-term. In the rare cases where parents' maintained contact by choice or due to reasons of subsequent pregnancy, parents were approached regarding study participation. However, due to these challenges, it was decided that the recruitment strategy would be expanded, to include non-NHS routes.

Non-NHS Recruitment – A substantial amendment was submitted and approved by the ethics committee (Ref: 11/H0717/6; Substantial amendment 9 SA09) to expand recruitment via non-NHS routes and include charity organisations such as the Stillbirth and Neonatal Death

Society (SANDS). Recruitment flyers were developed in collaboration with SANDS charity to expand the reach of study to parents from diverse ethnic groups (see appendix 3). These were posted in all social media accounts of SANDS charity as well as disseminated through the Patient Experience Research Centre at Imperial College London. The flyer included my email address, and an invitation to parents to contact me directly if they wished to receive further study details, and to consider participation. The flyers resulted in a healthy response from bereaved mothers from diverse ethnicities from all over the UK. An introductory email was sent to all mothers who responded, regarding the study along with the PIL and consent form. An introductory call was offered to discuss the study and explain the processes. At this stage a detailed explanation of the study was provided, including assurances of anonymity, confidentiality, and their right to withdraw from the study at any time. Upon successful consent, interview dates and time slot were finalised.

Interestingly, responses on the flyers were received only from mothers. One of the mothers who had reached out via the non-NHS route agreed to approach her husband regarding study participation, who later agreed to be interviewed for the study. This was discussed with SANDS charity as well as the PPI group, who pointed out that majority of the bereavement support groups are mother-centric, and fathers do not commonly participate in these avenues. Barriers faced by fathers from accessing societal support are well known(156).There are conscious efforts currently underway at SANDS charity to understand how support can be extended to fathers and to how best to engage them in ongoing programmes, despite the existing social barriers.

Figure 3- Participant Recruitment Pathway



3.2.3.2 RECRUITMENT OF NICU STAFF

NICU staff including doctors and nurses at the three participating NHS hospitals, who had the experience of working with newborn babies who died in the NICU and supporting bereaved parents, were invited to participate in the study. The study information was shared with the staff as part of study launch and introductory meetings. Staff were invited to respond to my request to participate in the study either by email or in person. This approach allowed sufficient time for staff to consider if they were interested in taking part in the study. A one-on-one meeting was arranged to discuss the study with all the staff who expressed an interest. A detailed explanation of the study was provided, including confidentiality and anonymity of data and an opportunity was given to ask questions. PIL and consent form were reviewed, and once study participation was confirmed and written consent was obtained, we arranged for a convenient date and time for an interview.

3.2.4 DATA COLLECTION USING SEMI-STRUCTURED IN-DEPTH INTERVIEWS

The aim of an interview in a phenomenological study is to focus on the phenomenon under exploration. It allows the researcher to explore events as experienced by the participant, and how he/she understands and perceives the world. Semi-structured interviews were chosen as the appropriate method for data collection in this study. In exploratory research such as this, it is even more helpful that views and experiences of participants are captured in a way that is flexible, and yet focussed. A semi-structured interview allows a dynamic yet focussed interaction between the participant and researcher (128, 146), while also being flexible enough to accommodate sensitive issues such as newborn death and emotional distress with an option of suspending interviews if needed. The flexibility of being semi-structured also allowed participants to weave their own narrative and avoid disclosing aspects that they were uncomfortable with. A semi-structured interview plan developing with inputs from supervisors and the PPI group, was approved by ethics committee and was also deemed as the most appropriate one by the PPI group.

The purpose of a qualitative research interview is to gather descriptions of the lifeworld of the participant and interpreting the meaning of the phenomenon (157). One-on-one interviews were suited to the hermeneutic phenomenological nature of the study. An interview in phenomenology is seen as a conversation rather than merely a process for data collection(157). The conversational nature of interviewing allows researcher to become immersed in the subject of data being generated by the study(158). However, treating an interview like a conversation also has risks of the interviewer influencing the flow of conversation or indicating their own biases. It is important for the researcher to be a neutral agent in the process(159). They must avoid imposing their own assumptions and fore-structures and remain open to the emerging ideas that may be very different from what the researcher expected(160). Therefore, maintaining a reflexive stance was important when conducting the phenomenological interviews. The reflexive diary aided this process as I attempted to reflect on my own stance prior to and after the interview.

In line with a phenomenological style of interviewing, a broad and tentative topic guide was used to facilitate an open and respondent led interview with participant. The topic guide was adjustable but relevant to the research topic to facilitate a credible and sensitive sourcing of data(128), covering various aspects from newborn's birth, admission to the NICU, care provided/received in the NICU to the baby's death. The questions were broad, for example, (for parents), 'Can you tell me about your pregnancy and child birth, 'Can you tell me about your experience in the neonatal unit?', 'How did you feel about the care your baby received?', 'Can you tell me about the death of your baby?'; and (for NICU staff), 'Can you describe a typical day in the NICU, 'Can you tell me about your experiences while caring for a baby who is likely to die or withdrawn care from?', 'Can you tell me your experiences of working with bereaved parents?', 'Can you elaborate on these experiences?'. More importantly, I had broad areas that I wanted to cover during the interviews. Often the need did not arise to ask all of the questions, and the interviews followed participants narratives while I endeavoured to maintain the focus of the enquiry.

The interviews were conducted at a mutually convenient time. Initially the study plan was to conduct in-person interviews but all stakeholders (all participants and myself) were hesitant as COVID19 pandemic was still unfolding, and I was in the second trimester of my own pregnancy. I applied for a substantial amendment to conduct interviews over Microsoft Teams, which was approved swiftly (Ref no: 11/H0717/6; Substantial amendment 11 - SA11). Thirteen parents and eight staff were recruited to the study and interviewed. All interviews, except for one, were conducted between September 2021 and January 2022 and one parent interview was conducted in March 2023, following my return from maternity leave. The interviews were audio-taped (using an audio recorder) with consent to capture all relevant information for analysis.

The reflexive journal was also used to take notes during and following the discussions, which included descriptions of my observations of emotional reactions, changes in voice-tones,

meanings and any other relevant information that could be used to help analysis. These notes were also helpful for me to recap and revisit any issues and their meanings for later explorations. Certain medical details shared were difficult to capture clearly in the audio recordings and the notes supported the process of revisiting the data and my immersing in it.

Member checking- Member checking, also known as participant validation, is a technique used in various methods of qualitative research for exploring the credibility of results(161). In this technique, data are returned to participants to check for their accuracy and resonance with their experiences. Relevance of member checking in phenomenology is debated. Some believe that member checking can be used to confirm the interpretations of experiences by conducting a second interview(128, 162). However, Gadamer argued that participant's narrative is time situated and from a particular horizon, which can change at a second interview(134). I understood both arguments but for different reasons it was decided that member checking would be inappropriate for this study. This was because of the highly sensitive nature of the study. I was aware how emotionally intense the interviews with parents could be and asking them to revisit the events felt unfair and disrespectful. Most importantly, I was not convinced that member checking would increase the credibility of my study. It seemed a step too far to resend sensitive data back to vulnerable parents and asking them to confirm if I had understood their grief and bereavement experience properly. As with all other aspects of research design, this was discussed with the PPI group and agreed that member checking is not suitable for this study. The participants were informed that a written copy of the findings could be shared with them if they wished. Throughout the study, I have tried to keep participants updated on the study progress. However, to date no parent has approached me to see the study findings.

3.2.5 ANALYSIS PROCESS

The methodology and analysis in this study was guided by Van Manen's Hermeneutic Phenomenological Reflection in conducting thematic analysis(128). The rationale for choosing

Manen's guidance on analysis over other approaches is discussed in 3.1.3. Manen provides principles involved in analysis and a guide to interpretation. This is instead of a formalised and reductionist approach, which is in line with the nature of hermeneutic phenomenology. Personally, as a researcher this approach allowed me to totally immerse myself in the data.

Hermeneutic reflection is central to Van Manen's (1990) analysis approach (128). He suggests that to understand the essence of a phenomenon, "*a process of reflectively appropriating, clarifying and making explicit the structure of meaning of the lived experience*"(128) (p77). In order to gain insight into the essence of a phenomenon, Manen suggests that themes should be used as structures of meaning(163) and proposes three steps for doing so. First, a "*wholistic [sic] approach*", where one understands the text as a whole by reading and re-reading the transcripts; second, a "*selective approach*", where one highlights statements that appear significant and are related to the phenomenon of interest and; third, a "*detailed approach*", where one considers every sentence, or a cluster of sentences to identify commonalities and themes(163) (p.92). Although, Manen does not explicitly discuss it, this process is consistent with the hermeneutic circle proposed by Heidegger, who describes it as a "*circle of understanding"*, where it is impossible to understand the whole without understanding the parts(145) (p.195). Although this approach is not prescriptive with definite steps to perform, in this study, analysis was performed in a systematic way to ensure consistency. A combination of the three approaches was utilised.

Transcription- I performed the transcription of all data myself by listening to audio recordings and creating the transcripts in Microsoft word. One of the main advantages in transcribing data is that it allows the researcher to become closer to the data(162). This was the main reason for undertaking this task completely on my own, rather than using any new technologies, or professional transcribers. In different ways, transcribing the interviews brought me closer to the meaning in participant narratives, through revisiting the interviews in real time in terms of tone, emotions expressed, emphasis and context. I continued to keep my reflexive diary while

doing the transcription. Transcription is also an early stage of analysis(157, 164) when key themes can begin to emerge from the text.

Analysis- The use of a specialist software to aid analysis was considered inappropriate for the study. I was concerned that using such a software might hinder my engagement with the data, interfere with the creative process of analysis, and lose the overall essence of emerging themes.

Following completion of transcription, all texts were read and re-read multiple times. This was part of the first step discussed previously in Manen's approach(128). This constant and repeated engagement with transcripts added to the overall 'feel' of the data. During this process, I oscillated between audio recordings and transcripts as it assisted my process of understanding the data. This process is relevant to hermeneutic phenomenology as the essence of phenomena is pursued.

Significant and revealing statements were highlighted and drawn out of the transcripts, according to the selective approach suggested by Manen(128). These sentences were read in isolation as well as collectively with the whole text. Sentences and clusters of sentences were brought together and at this stage I started grouping statements into preliminary themes, while continuing the circular move between the 'whole' and the 'selective'. This process is consistent with Heidegger's hermeneutic circle. Using Manen's guide to interpretation and the hermeneutic circle was essential for this study(128), as newborn death was a multi-dimensional phenomenon. Therefore, it was crucial to view the data in its entirety as well as in parts, to be able to carefully examine all aspects of this experience. The reflexive journal was also used, which helped me to constantly evaluate my fore-structures and evolve my thought processes during the analysis.

After identifying broad preliminary themes, I started using thematic networks. Thematic networks aid the process of qualitative analysis by systematically organising data, structuring

and depiction of themes and presenting in web-like maps(165). Due to the large volume of data collected, the use of thematic networks helped in visualising the themes in their entirety and facilitated the interpretation process. They also made discussions with supervisors simpler and enabled us to reach a consensus, through the visual audit trail. Using thematic networks I organised my main and secondary themes.

The final step in analysis process was writing. Manen argued that writing is an essential and central element in hermeneutic phenomenological analysis(128). Writing allowed reflection of ideas and interpretation to be formed and I continued the circular process of moving between data, thematic networks, and writing. As the writing progressed, my themes evolved, and I continued with "*re-thinking, re-flecting and re-cognising*"(128) (p.131). Throughout the analysis, writing was used to maintain and gain a depth of understanding of participant experiences and the emergent phenomenon. Writing and re-writing helped to continue to develop themes from descriptive notes into an interpretive text of understanding.

3.2.5.1 TRUSTWORTHINESS AND RIGOUR IN PHENOMENOLOGICAL RESEARCH

In any research it is important to produce trustworthy and believable findings. To ensure quality, the researcher adopts what is often termed a rigorous approach. In quantitative research, following a positivist paradigm, this is achieved by claims of validity and generalisability. It is because positivists accept one truth. This one truth enables the data to be generalised to the larger population and as a result dismisses the individual experience.

In contrast, in the interpretivist paradigm, where hermeneutic phenomenological research sits, rigour may be understood by the trustworthiness and credibility of data, reliability of the narrative and the resonance or meaning of the findings for the reader of this study(124). This paradigm rejects a hard objective stance and appreciates the uniqueness and individuality of human experiences. Lincoln and Guba stated, "Individuals create, negotiate, and interpret meaning for their actions and for the social situations in which they exist"(152) (p.34). As

objectivity and generalisability are not conducive with this school of thought, it is advised to maintain reflexivity in research(166). Being a hermeneutic phenomenological study, acknowledgement of my fore-structures of understanding was essential to the underlying philosophy. Reflexivity has been discussed previously in section 3.1.4 and will be a key thread running throughout the thesis. This also includes the researcher fully discussing the knowledge production process by maintaining a clear audit trail(162). Audit trail is ensured by maintaining transparency of the research design and methods, including rationale for decisions relating to the study, data collection and the analysis process. I have attempted to provide detailed descriptions of in the way analysis was approached in this study. However, due to the iterative nature of the study it is not possible to lay down the thought process involved. Moreover, it is important to state that while the steps taken in analysis of the study data may be replicable to an extent, it is unlikely that a similar interpretive analysis would be generated. It is because the different researchers will bring their own fore-structures, pre-conceptions and stance to the data(167), which is an important aspect of a hermeneutically phenomenological study such as this.

Finally, similar themes were apparent in differing accounts and for me further confirmed the trustworthiness and credibility of the participant's narrative. Narratives from all participants, (parents and staff) were heartfelt, emotional, and strong. I believe they were accurate personal accounts of their experience of newborn death. Although the passage of time may have affected their recall, it may have also allowed for a more reflective account(128), the assumption and the study stance is that there are multiple truths that are all valid and equal despite being produced in different ways. Generalisation of findings was not an aim of this study. However, the commonality of issues and themes propose that transferability of the findings is possible in a similar setting(166), which is an important aspect of understanding rigour and trustworthiness of data.

3.2.6 ETHICAL CONSIDERATIONS

Ethical decisions in neonatal care and research are guided by Hippocratic oath and principles of beneficence, non-maleficence, autonomy, correct medical facts and justice(168). A project about this subject matter, and of this complexity poses risks that are ethical in nature. The processes involved in such research often expose both, the researcher and the participants to a vast array of risks, and therefore require attention. This section discusses the ethical risks and considerations through different phases of the project.

Recruitment process

Recruiting bereaved families into research has a number of possible risks. To ensure that the ethical principles of autonomy, beneficence and non-maleficence are considered, careful attention to the recruitment procedures used is required. It was decided that due to the sensitive nature of the subject, parents who had experienced a newborn baby's death would be first approached for study participation by the clinical team. Since the final official appointment is organised at three months since bereavement, this was the first point of contact where parents would be introduced to the study briefly. However, shortly after the commencement of the recruitment process it was realised that parental grief was still very raw. It was feared that study participation may cause more harm and therefore, the recruitment process was expanded to use a non-NHS route (discussed in section 3.2.3.1). This route used social media networks of non-profit organisations for study advertisements, asking parents to volunteer if they wished to share their experiences of bereavement from newborn death. This process enabled parents to decide and respond to the invitation in their own time whenever they felt ready. On one hand by excluding those who were deemed 'at risk', non-maleficence was ensured, on the other, using a voluntary non-NHS route ensured parents' autonomy and right to beneficence was protected.

Consenting process

Another possible risk surrounds the consenting process. Emotional distress and trauma are factors that are known to have an impact on an individual's ability to think clearly, understand information and make informed decisions(169). In order to foster understanding, a consent form and a participant information leaflet written in a non-technical plain English was shared with parents. Parents were not given a strict timeline within which they needed to respond. Parental autonomy was hoped by allowing them adequate time to read, discuss with their family (if required) and understand what participation in a study of this nature could entail for them. Additionally, parents were offered an introductory call where the information leaflet was explained and discussed in detail. Parents were provided with an opportunity to ask questions. It was explained that participation in the study was voluntary, and parents were reassured about the confidentiality of the interviews and reiterated that at any point they could take a break from the interview, reschedule, or withdraw from the research, without any negative consequences. A similar process was followed with NICU staff who volunteered to participate in the study. Written and informed consent was obtained from all study participants before the start of each interview and for audio recording, to which all participants agreed.

Studies in paediatric bereavement have reported an issue termed as 'co-parent' consent, that is encountered when both parents are invited to participate in the study together or separately(170). Out of the thirteen parents who participated in this empirical study, there were three couples who consented and were interviewed individually. Although, this was not an issue experienced in this study, efforts were made to ensure that each individual parent has provided consent freely and independently and was not under any form of pressure to participate.

Data collection and interview process

Talking about sensitive, personal experiences of death of any kind may be difficult for participants, leading to a range of emotional responses from mild discomfort to significant psychological distress. Several studies have shown that even though participating in an in-depth interview concerning a traumatic personal experience is emotionally difficult, participants also found it therapeutic and beneficial(171-173). Despite these potential benefits, it was anticipated that some participants might show signs of distress when recalling their experiences. A risk management plan was developed with inputs from the PPI group. First, participants were encouraged to schedule the interview at a time of their convenience, to ensure they felt comfortable and safe in sharing their experience. For some mothers, it meant ensuring they were in their house with a stable internet connection, so they could talk openly and freely without any inhibitions. Second, to ensure the right support was made available for any participant immediately, I worked closely with SANDS charity and identified counsellors who would be available to extend support if needed. Ethnically representative bereavement support groups were also identified through SANDS charity, if participants felt the need to reach out to others with similar experiences from a similar social and cultural background. During the consenting process itself, participants were made aware of these provisions and were reminded during the interview process. It was also reiterated a number of times, that the interview process could be discontinued at any time and re-arranged if they were unable to continue the discussions any further.

The analysis process

Research risks are commonly discussed and considered with regards to participants. However, risks to the researcher in bereavement research are fairly documented(174, 175). While the researcher needs to manage emotions during the interview, the task gets more complicated at the analysis stage. As the study progressed, my engagement with the data intensified and I found myself constantly inundated with distressing images and stories from

parental narratives. The transcription process was a slow and constant reminder of the trauma experienced by parents. In order to grasp the essence of their experience I listened to the audio recordings multiple times. During this stage of the study, I was a new mother, and listening to parents' heart wrenching accounts I showed signs of potential emotional burnout. To ensure timely management of this risk, I enrolled in mental health support service provided by the Imperial College Health Centre and continued using this support throughout the course of the study.

Finally, ethical considerations of managing confidentiality are important when reporting the study results. In this thesis, non-maleficence was ensured by maintaining confidentiality of participants' identity. Pseudonyms are used for participants, defining characteristics are altered and minimal details are provided about participants' demographics to protect anonymity, with caution not to identify the hospitals where the child died as this could potentially identify the participants. Similarly, no information has been provided regarding staff's demographics, including place of work and ethnicity. As staff were interviewed from only three tertiary level hospitals in the UK, including even minimal details on background could risk breaking anonymity.

3.3 CONCLUSION

This study explored parents' and staff's experiences of newborn death. The study was guided by hermeneutic phenomenology, as discussed in section one of this chapter. This section has provided an overview of the study methodology, the theoretical underpinnings and clarified the rationale for choosing this methodology. The second section discussed the study design in detail, including the approach to sampling, recruitment, data collection, analysis and ethical considerations.

CHAPTER 4- LIVING THROUGH A LOSS OF AGENCY: PARENT'S LIVED EXPERIENCES OF BEREAVEMENT AND NEWBORN DEATH

4.0 INTRODUCTION

In this chapter I will explore the lived experiences of parents whose newborns died in the NICU. Living through a loss of agency emerged from the data analysis as the key phenomenon. This is important for this hermeneutic phenomenological study as it helps to capture the essence of parents' lived experience of the NICU and their newborn's death. It gives meaning to their experience of their 'being' in the world of NICU. Through this chapter I aim to give an insight into their lifeworld with the phenomenon of loss of agency being at the centre of the analysis. The chapter is divided in two sections- Section one – Participants and Section two – Themes and Interpretation.

4.1 SECTION ONE- PARTICIPANTS

This section introduces each parent who participated in the study and descriptions of their reports of their lifeworld. Thirteen parents (9 mothers and 4 fathers) agreed to participate in the study. All participants gave me an insight to their lifeworld, as lived, perceived, and experienced by them. Their lifeworld is a significant part of their story and crucial to understanding the phenomenon that was unveiled. I have given pseudonyms to all parents and their babies (wherever used) and eliminated all identifiable information to preserve anonymity. Referring to them by names rather than numbers felt more significant in giving them an identity and a voice. All the stories came bundled with emotions and memories. I have

tried to retain their originality as I felt I had a responsibility to do so. In introducing and describing participants, I have not followed any a priori format. Their story guided the writing, determining a unique flow and length for each.

4.1.1 ANNA – INTERVIEW 1

Anna was 36 years old when she got pregnant with Danny. She had high blood pressure during her pregnancy. Her medical team feared that she would have preeclampsia and as a result there was a constant back and forth between hospital and home throughout her pregnancy. Her unborn son Danny had ectopic heartbeats, but she was told there was nothing to worry about. Her pregnancy was described to her as a "*horse running in a race and then jumping a hurdle*", and yet she was not adequately prepared for any adverse outcomes. Danny died when he was 5 days old in the NICU. She talked about Danny and his death, as if it happened yesterday. Anna wrote poems in the memory of her son and the failed motherhood she felt she had. Poems also allowed her to express her grief without causing hurt to her loved ones. She shared those poems with me, as she believed they illustrated her grief better than she could. With her prior consent, one of the poems is shared in the conclusion section of this chapter. In the middle of the interview, she asked me if I wanted to see Danny and then lovingly showed me his photograph from the hospital. She worked as a payroll supervisor in a factory and went back to work shortly after her bereavement. Nine months later she got pregnant with another boy. This child was born healthy, but her pregnancy was traumatic as she relived the horrors of her previous childbirth and loss. She identified as White-British and followed the Church of England. Anna was 49 years old at the time of the interview and her relationship with God has been a turbulent one since Danny died.

4.1.2 SARAH – INTERVIEW 2

Sarah was 19 years old when she got pregnant and had her first daughter. It was a straightforward pregnancy. At 40+2 weeks she felt her waters had broken and went to the hospital, where she was discharged home without adequate investigation. It was at 41+6 weeks when she went into labour, finding herself in agony. Sarah shared that at this stage she had maternal sepsis but did not disclose any further information on this. She described feeling neglected, yet again, and felt that the midwives did not check the baby's heart rate. She believed this was the reason her daughter was born without a heartbeat. She was resuscitated for 26 minutes and died three days later. An investigation was launched by the Healthcare safety investigation branch due to the unexpected nature of her baby's death. Sarah studied photography in college and worked as a barmaid, but this experience changed her outlook, and she is now interested in pursuing law. Although still ongoing at the time of interview, the investigation had given her answers and relieved her of the immense guilt that complicated her grief. Both she and her partner fell into depression and continue to live with post-traumatic stress disorder (PTSD). Unable to understand what would help her move on from her trauma, she decided to try for another baby and got pregnant within 2 months of her bereavement. She was 19 when her daughter passed away and it had been a year since then, when I interviewed her. She came to the interview, albeit virtually, with her second newborn infant. Sarah was born in a Catholic family but prior to her lived experience of bereavement, she and her partner were not religious. In the hope for a miracle, their daughter was baptised in the NICU. Few months later she and her partner decided to get baptised as they wanted any connection that was possible with their first-born daughter. Although unsure if heaven existed, she did not want to leave any opportunity of a reunion with her first-born daughter and to see her again someday.

4.1.3 JANE – INTERVIEW 3

Jane was 31 years old when she got pregnant with twin boys. She worked as a teaching assistant and lived with her husband and their two children. Born in a family that followed the Church of England, Jane identified as White-British but claimed to not follow any religion. The pregnancy started off without complication, but as she reached the 19th week, she started developing complications. They learnt they had twin-to-twin transfusion, and as she mentioned, it was a frightening journey thereafter. They were referred to a super-speciality hospital, to undergo a procedure that would separate the twins and give them their best chance of survival. The procedure was successful. However, Jane went into labour at 24 weeks and with all the efforts to prolong birth, the boys were born at 25 weeks of gestation from a caesarean section and were taken directly into the NICU. Her husband followed the boys as she waited for information on their well-being. She described her feelings in those moments when she could not get up to see the boys due to the anaesthesia. She felt that the minutes were *dragging* as she watched the door waiting for her husband with information. She was alone as it was during the COVID19 lockdown. The pandemic made the experience even more challenging for her, as her two older children could not meet their brothers. She found herself experiencing absolute powerlessness and no control over her life. Her first son (Zen) had a few bleeds on his brain, which eventually resulted in his death. The doctors counselled her that even if Zen had survived, he would have been brain damaged. However, her second son, Jon, had no complications other than that he was born pre-term and needed to grow bigger. Jon died because of infections from milk that entered his lungs due to multiple accidents when he kept pulling his nasogastric tube out. Overall, Jane was satisfied with the care that was provided to her and her boys and it made her grieving tolerable because she knew that the medical team did everything, they could, to save the boys. One year later, at the time of the interview, Jane had already given birth to twin girls born at 29+1 weeks, and she described her subsequent pregnancy as reliving a nightmare.

4.1.4 DOLORES – INTERVIEW 4

Dolores was 45 years old when she found out that she was pregnant. It was an unplanned pregnancy as she had recently given birth and had an intrauterine device fitted. Dolores is a healthcare worker, a mother to a 17-year-old girl and a Roman Catholic of Asian descent. Her previous pregnancy was complicated due to gestational diabetes. She was called for a dating scan to establish the due date, where the medical team realised potential complications with her pregnancy. Thereafter, she was offered a chorionic villi sampling, which diagnosed that her baby (a girl) had Edwards syndrome (trisomy 18). She described that it meant that her baby's life was rendered impossible. She remembered that she was around 12 weeks pregnant and was offered a termination of pregnancy. It was not a decision for her to make by herself, so she shared with her family. For the family it was a sudden rollercoaster of emotions. The family collectively agreed to terminate the pregnancy but when she was at the hospital for the procedure, she found herself remembering her baby's movements from the scan. It made her realise that she (her baby) had already developed as a human being. Being a healthcare worker meant that she was conscious of the reality of trisomy 18, but it was against her belief as a catholic to terminate the pregnancy. The couple decided to go ahead with the pregnancy, and unlike other pregnant women and families, they prepared for their baby's death. Due to poly-hydramnios, she was booked for induction at 35 weeks. However, the baby's position was not deemed safe for a normal vaginal birth and the medical team decided she would undergo a caesarean section. But this decision was made after a complex period of apparent indecisiveness from the clinicians, who first started her on medication for induction. She waited to give birth for nearly two days and during this period she had requested the baby's heart be monitored; a request that was denied. Later she found herself bleeding heavily and was rushed for caesarean section. She was administered general anaesthesia because an epidural failed, and she stated that she *could feel everything*. She shared that it took her longer than usual to wake up from the general anaesthesia, but she could not spend enough time with her daughter who died a few hours later. Three years later, at this interview, she shared

how she felt neglected in clinical care and deprived of the opportunity of being with her baby, only because she *was not compatible with life*.

4.1.5 MARIAM – INTERVIEW 5

Mariam, a British-Pakistani woman, got married in November 2019 and found out that she was pregnant a few months later. It was an unplanned pregnancy, complicated by her epilepsy; she was taking sodium valproate medication. She was unaware that it was possible to change her medication to something that is safer for consumption during pregnancy. Out of fear for her baby's safety she discontinued the medication without any medical consultation. This caused her to have a tonic-clonic (grand mal) seizure. She was rushed to the hospital, where they changed her medication and performed an ultrasound scan to make sure the baby was fine. At her 20th week appointment, the medical team found some anomalies in her scan and blood report and wanted to investigate further. She was referred to a super-speciality hospital where she was given multiple diagnosis, including some issues with the baby's heart. However, nothing was confirmed to her, and she remembered how it was difficult for her to understand and grasp it all. It was her first pregnancy and due to the COVID19 pandemic her husband was not allowed for any appointments, despite their multiple requests. He is an immigrant from Pakistan and was not comfortable with communicating in English. She found the experience overwhelming and felt unsupported from the beginning; she said, *I just felt lonely the whole time*. Even now her memory was failing her as she tried to remember the details of what transpired. Eventually she was told that her baby had pulmonary atresia with a ventricular septal defect, but it was *again* without clarifying the severity of these diagnoses. The clinical team gave her advice and details on the support her baby (boy) would need after birth, including monitoring his heart regularly as well as the fact that he may have special needs. At some point earlier in her pregnancy, she was also offered termination, but her Islamic beliefs were against such a decision. Moreover, she believed being a pre-school teacher herself she was equipped for looking after a disabled child. At her 37 weeks appointment, Mariam's medical team realised that her membranes had already ruptured,

although she had not noticed. She was sent for induction soon after. The nurse who initiated the process was not aware of her pregnancy complications and she described the induction process caused the baby's heart rate to fall. Mariam was rushed into an emergency caesarean section. The baby was admitted to the NICU immediately after birth. She had to wheel herself into the NICU as her husband was not allowed at the same time because of pandemic restrictions and she felt she was not offered support from the hospital staff. A few days later, her baby was taken into surgery, which they were told was minor and were given high hopes of success. However, the baby did not survive. She remembered being told what had happened. However, the staff had used medical terminologies and phrases which she did not understand. During the 11 days in NICU, they had minimal communication from the medical team about their baby's prognosis, treatments, and potential outcomes. She felt discriminated against because of the colour of her skin and ethnicity. It had been two years since her baby's death, when she was interviewed, but she still appeared in disbelief about the outcome.

4.1.6 CLARA – INTERVIEW 6

Clara was 35 years old when she found out she was pregnant with twins. The pregnancy followed multiple fertility treatments. She remembered that it was Good Friday when they learnt about the pregnancy. The significance of that day stood out her in memory. Clara's pregnancy was "*horrible"*, including several hormonal issues as well as pelvic girdle pain that affected her mobility. It caused her severe anxiety and she found herself constantly depressed. She tried to contact her midwife a few times to seek help regarding her mobility issues and anxiety but received no response. Clara was 22+6 weeks pregnant when she and her husband were visiting a family in another city. On the drive back she realised she was bleeding heavily, and they hurried to the nearest hospital. She was in labour, fully dilated with bulging membranes. She remembered she was trying to remain calm as she was told by the medical team that it was too late to do anything. She was told that she would give birth naturally and they would hold the boys in their final moments. She was in labour overnight, grieving in anticipation, when one of the nurses told them that after discussion with consultants it was

agreed that they would estimate the birth weight of both babies and if they weigh at least 500grams, they would pursue treatment. Shortly after this discussion, the boys were born, and they passed the test of viability. She remembers being in shock and not saying a word. However, she also felt an appreciation of her situation, because one day earlier the boys were going to be dead and now, they were being transferred to a Level 3 NICU. Thirteen years later during the interview she was having a flashback of the moment the ambulance doors shut and the boys left for another hospital. She said *I just buried my face in Roy* (her husband), *and I just cried and cried and cried… because now they're gone*. Her first-born son, Olly died when he was approximately 3 weeks old. The second twin, Henry is living with autism and has a younger brother. Clara, who identified as a Black-British woman of Caribbean heritage following the Church of England, is now an advocate for family integrated care and respectful communication in the NICU.

4.1.7 ROSE – INTERVIEW 7

Rose was a mother to two girls and worked as a Nanny. She identified as a White-British woman, who was a member of the Church of England. She and her partner Patrick were thrilled when they found out they were having a boy. Although, she said that her pregnancy was relatively normal, she had recurrent scares when her medical team thought the baby had Trisomy-18 at 12 weeks and a heart defect at 16 weeks. Both the tests revealed normal results and they were looking forward to welcoming a boy in the family after two girls. Late one night when Rose was nearly 24 weeks, she woke up with stomach cramps, that she thought were from indigestion. A few minutes later the cramps got stronger, and she was able to time them. She did not believe that she could be in labour. Her family hurried her to the hospital, where her labour was confirmed. Her cervix was fully dilated, and she gave birth to Patrick Junior who weighed 565 grams. She remembered when she met him properly for the first time in the NICU, he was already intubated. Patrick Junior died a few weeks later and his death was attributed to prematurity and infections due to lack of any evident cause. Rose was in her subsequent pregnancy when they found out that she had an incompetent cervix that caused

her to go into premature labour. She shared how it was a bittersweet feeling because even though this realisation prevented her from another premature labour and saved her unborn daughter, she also felt guilty knowing that her body was the reason causing her son's death. She needed counselling support to cope with her grief and guilt but found it inadequate and disrespectful. She often turned to bereavement support groups organised by charity organisations like SANDS. To honour the memory of Patrick Junior and also to acknowledge her bereavement journey, she started organising fundraisers for SANDS charity with a hope to extend support to other grieving parents who did not feel adequately supported by the NHS. Rose was in her third trimester when she agreed to participate in the study.

4.1.8 PEARL – INTERVIEW 8

Pearl was in her 40th year when she got pregnant. She identified as a Black-African of Ghanian heritage and was a Christian. She had a history of fibroids which made it difficult for her to conceive and she had been told by the gynaecologist that she was not ovulating. She had a hectic job as she worked as a customer relations officer in a bank, which she found stressful. It was a pleasant surprise for her when she found out about the pregnancy. However, she had a very difficult pregnancy, where she was often in and out of the hospital. She shared that she had placenta previa, as well as pulmonary embolism. She said she lost her appetite and was rapidly losing weight. The scans also showed that her unborn daughter (Imelda) had a prominent sized hole in her heart as well as Down's syndrome. She was asked if she wanted to terminate her pregnancy, which she refused. Both Pearl and Imelda were not gaining weight and it was suggested that she would undergo a caesarean section at 35 weeks. After birth, Imelda was admitted in the NICU and a few weeks later transferred to the NICU of a super-speciality hospital. A few weeks later the COVID19 pandemic created contact restrictions, accentuating her sense of helplessness. Imelda had pulmonary hypertension and the pressure was very high on her lungs because of which she could not have her heart surgery and died few weeks later. She felt that throughout her pregnancy emphasis was given on Down's syndrome, whereas all she wanted was for her daughter to survive.

4.1.9 JANNAT – INTERVIEW 9

Jannat had a straightforward pregnancy till 24 weeks, when she went into premature labour. She and her husband rushed to the nearest hospital. She gave birth to her son who was then moved to a tertiary neonatal unit in another hospital in a different city. After being discharged from the postnatal ward, she and her husband moved into the hospital accommodation. Her husband was not comfortable communicating in English, and she was leading all the conversations with the medical team, even though she felt she was not equipped to do so. She tells how she was naïve enough to believe that everything would be fine, and her son would get better and go home with them. He had a brain bleed and died one month later. Ten years later she regrets not taking any pictures of him, especially when she had been offered the opportunity to do so. She came from a conservative British-Pakistani and Islamic family background, where was not allowed to vocalise her grief. Her naivety prevented her from taking a stand for herself when she was not permitted to attend her son's funeral. A few years later she gave birth to her daughter at 26 weeks, whom she brought home. She said this time she tried to change her narrative, by being more vocal and demanding, both in the NICU and at home. To this day she continues to participate in meetings organised by charity organisations, who supported her to find her path in grief and accept her new reality as a bereaved mother.

4.1.10 PATRICK (HUSBAND OF ROSE) – INTERVIEW 10

Patrick, husband of Rose, identified as a White-British male without any religious beliefs. He had minimal involvement in Rose's pregnancy due to COVID19 pandemic. He described how the pregnancy felt completely okay until they were in the ward with Rose in labour. Throughout the interview he was very reserved and seemed hesitant in expressing his emotions. He remembered his son Patrick's birth and how after his transfer to the NICU he stayed back with Rose to help settle her down and get ready to go to the NICU. He mentioned that even though it had been only a couple of years, he was having a difficult time remembering the details as he had blocked it all out. Blocking those memories was his coping mechanism, which helped

him carry on with his life, be a good father to his daughters and a supportive partner to Rose. Although no child loss is easy, for him losing his son was particularly difficult. Patrick Junior was going to be the first son in the larger family and his name had been passed down to him from three generations. As he shared his memory of his son being a tiny baby hooked to multiple machines with his translucent skin, he seemed uncomfortable and uneasy. Even though he was appreciative of the study, participating in the interview brought him back all the unpleasant memories of NICU and his son.

4.1.11 ROY (HUSBAND OF CLARA) – INTERVIEW 11

Roy shared their story of fertility treatments and how both he and Clara were thrilled that they were having twin boys. He identified as a White-British man following the Church of England, excited to raise a family of mixed-ethnicity. With the events that unfolded he talked about trying to remain strong for Clara as they both needed that. He remembered being in the labour room surrounded by other mothers giving birth, making him feel happy and sad at the same time. He worked in a pharmaceutical company and had prior exposure into the world of intensive care. However, his personal experience of NICU made him feel *isolated, exposed,* and *helpless like never before*. In between all the negativity and uncertainty, Roy also talked about *beauty in adversity,* and this helped me to define the theme on the role of kindness in NICU.

4.1.12 PETER (HUSBAND OF JANE) – INTERVIEW 12

Peter was 32, a religiously agnostic White-British man who worked as a process technician at a power station. He talked about their pregnancy journey, finding out they were having twins, complications of twin-to-twin transfusion, Jane's birth story and their NICU journey. He shared how with his first son Zen, he had expected the outcome of death because Zen had severe hypoxia since birth. However, he struggled to accept what happened with Jon (his second son). In the 36 days that Jon lived, there was a lot of hope. He was not on any medication or cannulas when he died because of pulling his tube out. Peter felt he (Jon) probably got tired of trying and wanted to be reunited with his brother Zen. Jon died a day before Zen's planned

funeral day and the family eventually organised a send-off for both the boys together. Prior to this experience Peter was not spiritual, but the connection that he felt between the twin boys made him believe in miracles and the thought of his boys being together brought him comfort.

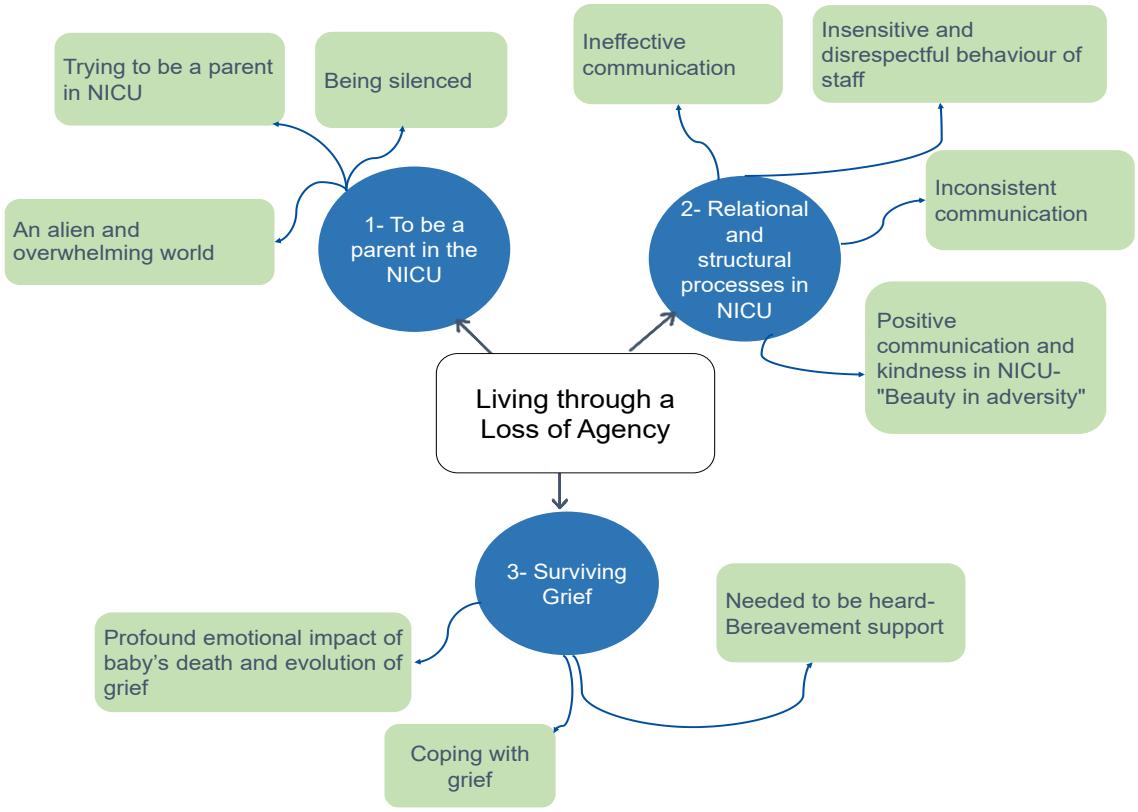
4.1.13 STEVEN – INTERVIEW 13

Steven and his wife were on their honeymoon when they learnt about the pregnancy. It had been seven months at the time of the interview since he and his wife had twins (a boy and a girl). He said the pregnancy was *"too good to be true until all hell broke loose"*. At 24 weeks, Leo and Lilly were born from an emergency caesarean after Steven's wife went into premature labour. He shared his memory from the traumatic experience of the doctors struggling to resuscitate and intubate Leo, whereas Lilly's was relatively easy. He wondered if that was a step towards Leo's brain bleeds and his death 4 days later. His wife had an autoimmune disease, for which she had a blood test 5 weeks before she gave birth. The results were expected in 24 hours but despite repeated chasing, they did not hear back. It was 5 weeks after their birth that they received a letter stating the complexity of her condition, asking for urgent attention, and increasing her medication. At the time of the interview, he was still not sure but wondered if it was the cause of premature labour. He talked about the emotional challenges of being a parent in the NICU and compared the volatility to his experience of starting a business on his own. He was the director of his own recruiting company but described the NICU experience as the most challenging and unnerving period of his life. He had also set up a charity organisation to honour Leo's memory, life and struggles in the NICU and raise funds to support neonatal care of premature babies. Lilly was discharged from the NICU at around 4 months of age and continues to prosper as a growing infant. Steven was religiously agnostic and identified as White-British.

4.2 SECTION TWO – THEMES AND INTERPRETATION

This section presents findings that emerged from the rich narrative data provided by parents from experiencing newborn death in the NICU and the interpretation that led to development of themes and the phenomenon. Themes and sub-themes are explored and discussed individually and together to facilitative understanding of the overall lived experience. Commonalities and diversities in experiences was sought and are presented in the chapter. The analysis revealed three broad themes, 1) To be a parent in the NICU, 2) Relational and structural processes in the NICU, and 3) Surviving grief (refer Figure 4). There are further ten sub-themes, which aided breaking down of understanding and interpretation and finally bringing it back together to understand the phenomenon, as a whole (see Figure 4). The volume of participant quotations in the text is intentional, as I believe they reflect the essence of experience and carry the weight of the phenomenon. The quotations are primarily verbatim with minimal edits to retain the emotions behind each story. Most of the quotations are emotionally dense and may be distressing for readers, especially parents who have undergone bereavement.

Figure 4- Diagrammatic representation of thematic analysis of parental lived experiences.



4.2.1 THEME ONE - TO BE A PARENT IN THE NICU

The first theme provides an insight into the parental world of NICU. This theme has three further sub-themes to understand the complex relationship parents shared with the NICU environment; 1) An alien and overwhelming world; 2) Trying to be a parent in NICU; and 3) Being silenced. Through the rich narrative data, I deep dive into the overwhelming, turbulent, and terrifying reality experienced by parents. They grappled with dependence, loss of control, and yet also found moments of joy and gratitude. Positive and negative feelings towards the NICU co-existed in the lived experience of parents, and while none of them wanted to revisit their NICU days, it remained an integral part of their lives.

4.2.1.1 AN ALIEN AND OVERWHELMING WORLD

Parents initially entered the NICU as visitors, for whom it was an unfamiliar world that soon became an integral part of their lives. The journey was often experienced as *surreal*, and most parents were unprepared for what lay ahead. Most parents had no prior experience of an intensive care unit and more specifically, the NICU, and therefore were unaware of what to expect. They felt overwhelmed, witnessing babies linked-up to machines, some invasive and others non-invasive; surrounded by noises, lights, medicines, and staff who were always busy, going about their day doing important duties and tending to these babies.

> *"When you're expecting a healthy baby, you're a low-risk pregnancy. You don't think about the ward then, obviously. When she was going in the ward this whole, their whole world opened and there's all these little, tiny babies and all these poorly babies. We'd never even thought about it before at all. That was horrendous". (Sarah)*

The unfamiliarity was experienced differently by mothers who were often recovering after a difficult birthing experience. They felt disconnected from the environment and took time to grasp the gravity of situation. In describing her thoughts, Pearl narrates how seeing her newborn baby hooked to the machines felt like an alienated scenario to her being. Despite her complicated pregnancy seeing her *tiny* baby in a highly intensive atmosphere, was not an expected outcome for her.

> *"It is extremely frightening and maybe because I had just, you know, I I was recovering. It's almost like you don't know what's happening. You you come upstairs to this neonatal room to see the baby hooked up to all these machines and I didn't know what was happening. I just thought when are we going home? I didn't. I didn't really know what was happening. And I wasn't really listening to what they were saying because I just wanted to take her home. She stayed there for a while and you know she was very tiny…You know? She was the size of my hand and thought she was even smaller than that". (Pearl)*

Parents closely observed the medical devices, seeing their baby's oxygen saturation levels, their ECG rates, and their heart rate. They reported following the lights and noises and absorbing every piece of important information that NICU generated. They were aware of their (their baby's and their own) dependency on these medical technologies but also harboured a dislike towards them and a strong resentment for having to be in that environment. Perhaps it was so, because even though the technology was keeping their child alive, it also created a barrier between them and their baby.

> *"And all the machines, the noises oh! I hated the noises. Obviously you have all the noises of that..all the machines in the NICU. Yeah, but you obviously, that's… You know that's what's keeping him alive. But you'd have like a whole bank of machines. We've… you know where they, the little injections on the sides that would be injecting across you know all the stuff that he needs. And see you know you'd have all of that. And then you have one machine that was completely falling out of it. Then if they know some point later, another machine it was next to and I thought bloody hell, you know all these things that we're sort of stuck in". (Patrick)*

Parents described a relentless *rollercoaster* of emotions marked by persistent anger, fear frustration, and isolation, which contributed to an overwhelming sense of vulnerability and helplessness. The unpredictability of situation was challenging for parents. For most parents, it felt like living in the *eye of a storm*, while needing to remain composed and carry on. Some parents also expressed the unexpected coexistence of joy and anger, an emotional juxtaposition they felt they were ill-equipped to manage.

> *"It's it's just never-ending rollercoaster emotions. I've never experienced a dichotomy of emotions like I did in NICU, you know, obviously for me it's to having that immense happiness and immense sadness at the same time is something I'd never expect". (Steven)*

“You know they say it's a rollercoaster ride it… It really is because one minute they're saying…yeah, there are some positives and then then.. you know…they're saying there's a lot of negatives”. (Patrick)

Parents oscillated between hope and hopelessness. They were aware of the severity of the situation, yet always had hope and expressed gratitude for small victories and successes in the NICU. The prospect of a future with their babies protected them and gave them strength and resilience to persevere. At the same time, this hope also created an inner conflict, and they found themselves torn between the desire to give up and clinging to that faint glimmer of hope of their baby’s survival.

“I'm kind of torn because I.. I.. I.. was kind of torn in truth, because you're right, I was in a very very stressful situation. I probably…[field notes suggest that while talking participant was also trying to make sense of his experience and memories of the emotional struggles in the NICU]… *It would be hard to make it much more stressful on a like a regular…You know, over the regular whole of the week, but there were moments where it could become more stressful, but I'm reflecting on this at the time when I was thinking… I don't want to believe what you're telling me, but I've been brought up to believe an expert and repeatedly now it's been drummed into me that this is and so… I think it forced me to be in conflict with myself, which if you've got that inner voice fighting.. Umm... It is very energy consuming. So it made me really, really tired and it made me quite… A little bit snappy and a little bit like… You know, I said isolated and exposed at the top at the start, like I'm a very positive person, but quite I would describe it as…just like a bit lost just. How do I keep my energy and strength go and nothing seems worthwhile here”. (Roy)*

Some parents described their experience in the NICU as like an out of body one, as if they were observing themselves from a distance while operating on *autopilot*. Their minds and bodies seemed disconnected, and they struggled with that version of themselves. This surreal

situation was one in which they never imagined they would find themselves. With all the uncertainties and unknowns, it felt more like a strange and shocking dream from which they hoped to awaken.

> *"Because I knew he was dying. And I want to be with him. I cant really describe it. It's such a weird situation. It's like you're watching a video of yourself. And you walk across the room and you think oh, she's going there now. I'm like you're watching yourself it's. It's almost like an out of body experience, it's…You know you're there, but you can't believe it's happening to you. You think I'm not going to wake up in a minute? And you realise, no, this is real. This is happening". (Anna)*

The unfamiliar world of NICU became an all-encompassing world for parents, who found themselves living in and out of the unit. Irrespective of the days they spent there, they experienced it like a lifetime, where their baby lived and died.

> *"It is very overwhelming at the time…And* [field notes: participant took a long pause here. It seemed she was trying to remember her experience and reflect on it at the same time] *… but we didn't realize it was overwhelming because we were just in it. you just on alert all the time. It's only afterwards when you get a chance to think about it, but you come crashing down". (Jannat)*

4.2.1.2 TRYING TO BE A PARENT IN NICU

Being a parent in NICU was challenging for the parents due to the uncertainties and critical condition of their newborn baby. They were constantly fearful for their child's survival. Moreover, this situation led to an unexpected dependency on the staff and circumstances, which dictated how they could be a parent to their babies. They felt the unfathomable helplessness when they could not provide for their own child, a role that is primal to parenthood. Not being able to hold their own baby without someone's help, look after them, provide for them, and make decisions about their care, was very unsettling. Their reality of

being a parent was in stark contrast to what parents had envisioned for themselves before they found themselves living it.

> *"Scary and not being able to do anything for your babies...relying on other people to help them…when you feel that you should be doing that, you should be the one looking after him. You should be the one doing this and… You need to be calm because you've got no idea what you need to do to keep them alive. Silver lining on all them people, all their machines. And those people's brains to…look after and keep your baby alive. Scary, really scary." (Jane)*

Mothers described how incapacitating it all felt, needing to ask for assistance to pick up their own child, and sometimes being denied that opportunity or not wanting to upset the staff by appearing to be an overly *needy parent*. Some mothers also experienced a sense of betrayal, feeling that people who were meant to care for, support, and protect them, were denying them the simple act of cuddling their own child. This sense of betrayal undermined the trust they had placed in their caregivers. They felt helpless and at the mercy of the care providers.

> *"I said I've come for a cuddle, and they said, well, we've just settled him. Leave him alone, we've just settled down. Should we not be cuddling?..* [field notes: participant was crying while recalling her experience. The feelings of helplessness and betrayal that she felt in the NICU seemingly remained with her]. *Well, they wouldn't let me because they just settled him". (Anna)*

The helplessness experienced by parents was exacerbated by feelings of guilt for not being their child's primary carer and for leaving them in the NICU. Some mothers blamed themselves and their bodies for failing their babies, while others felt like failures for not being able to help them.

> *"You know you cry, you scream. You are in disbelief. You, you feel like a failure, you can't even help your child"* [field notes: participant was crying inconsolably as though she still feels her helplessness of not being able to help her daughter] *(Pearl)*

Parents demonstrated a deep need for proximity and closeness, expressing the desire to be in the NICU and maintain a constant presence at their baby's side. After giving birth, mothers rushed to see their baby as soon as they were able to do so. An intrinsic part of being a parent involves carrying out basic yet essential tasks like changing a nappy, bathing, and dressing your baby; tasks that many parents only had the chance to do after their baby had died. Most parents felt a deep need for closeness to their baby, longing to hold them and to establish a strong connection. Even though these moments were filled with extreme pain, parents appreciated being given privacy together as a family and spending some final moments together.

> *"I wanted to be the one with my hands on him. There's something about touching my baby. So I I was crying. I couldn't really see, but I think it might have been shaking a bit and I couldn't get their probes off. I said oh sorry, will you do it? I just wanted him so badly. I just want to hold him". (Clara)*

During the COVID 19 lockdown, when parents were not allowed in the NICU together, they took turns being there. Wherever possible, especially for first-time parents, they stayed at the hospital and were present from early morning to late evening. Being there meant everything to them, and when they could not be present, some mothers talked about experiencing intense guilt for leaving their child behind, which further exacerbated their feelings of helplessness and frustration.

> *"I didn't really find peace at all because I was so stressed about him and every... still guilty if I left him. If I wasn't with him like I'd feel so guilty when I would go back to the hotel back to the room to sleep in, but I would feel so guilty really give me for not being with him that 24/7". (Mariam)*

4.2.1.3 BEING SILENCED

Being a parent in NICU came with numerous challenges, some of which have been explored in the sub-themes above. The feelings of helplessness and vulnerability experienced by parents in the NICU were further intensified by a loss of autonomy when their actions were seemingly controlled by the clinical staff. This sentiment was predominantly shared by mothers, who were either '*not allowed to go natural*' or '*not allowed to go in the ambulance* (with her son)', illustrating their absolute lack of control over their own experience. They did not want to be perceived as *difficult*; they felt guilty, were wary of annoying the staff by asking too many questions or voicing their concerns and did not want to be a burden. Few mothers associated their experiences with cultural restrictions typically imposed on women, where they are often expected to be non-confrontational and accommodating. However, in this scenario the imposed silence was perceived rather surprising and ironical by mothers, because in a hospital environment, they expected receiving care and protection, instead of feeling marginalised and silenced.

> *"We need to get something because I mean culturally* [African-Ghanian]*…we have people like you know.. who say no, these women should suffer in silence. You know these things shouldn't happen; you know. It will give them such devastating news. The NICU is frightening…you know it's frightening".* [field notes: Although she was crying participants' tone reflected anger, frustration and a feeling of destitution] *(Pearl)*

> *"We didn't want to cause any problems…. it's hard really, really, really hard, and I think across healthcare in general. And then almost… the scarier it is the quieter the patient or the parent becomes". (Clara)*

4.2.2 THEME TWO- RELATIONAL AND STRUCTURAL PROCESSES IN NICU

From the prior theme, it was evident that parents often felt helpless due to their heavy reliance on staff for allowing them to be a parent to their child. Additionally, an absence of a functional

interpersonal relationship with staff, coupled with certain structural barriers, appeared to hinder parents in fulfilling their needs and obtaining the necessary support in the NICU. In this second theme, I delve into the lived experiences of parents in the NICU as influenced by these relational and structural processes, and how these processes further contribute to the loss of agency and feelings of disempowerment. This theme is divided into four sub-themes, 1) Ineffective communication; 2) Insensitive and disrespectful behaviour of NICU staff; 3) Inconsistent communication; and 4) Positive communication and kindness in NICU- "*Beauty in adversity*". Communication with the NICU staff stood at the heart of parent's interpersonal experiences. Being in an overwhelming environment with multiple barriers to effective communication, emerged as a significant challenge for parents.

4.2.2.1 INEFFECTIVE COMMUNICATION

Parents frequently cited the lack of effective communication with the NICU staff as a significant obstacle. The staff often seemed to misunderstand parents' needs, particularly in terms of communication within the NICU. From discussing prognosis and treatments, to addressing the unpredictable changes in the newborn's condition, many parents expressed dissatisfaction with the manner in which information was relayed to them. Some parents noted an absence of sufficient information sharing, which occasionally affected their ability to grasp the seriousness of the situation.

> *"…while he was… in the unit* [NICU] *we weren't kept informed about anything, which is something I do want to complain about now. He was there for 11 days… so that's quite a long time… It's not that long, but it was at the time". (Mariam)*

On the contrary, some parents felt that the staff shared unnecessary minute details about their child's condition, which they deemed unimportant and found to contribute to their stress. While parents recognised the challenges faced by the staff in striking the right balance, they expected the staff to make efforts to understand each parent's unique situation and tailor communication to their specific needs.

"They [Staff] are telling us too much about… this medicine has caused this to happen, so now we're giving him another medicine for that, and then it was a bit too much for what we needed, really…really is it.. Is it beneficial for the parent to know in that much detail"… (Jannat)

Parents expected the staff to exhibit greater empathy than they did and acknowledge their emotions and anxieties while providing support and comfort during this challenging time in their lives. There was a perceived lack of individualised care in the NICU. Beyond attending to the specific needs of the parents, some parents felt that staff should have assessed what information parents required, their mental state, their level of comprehension, whether they needed more information than what was already provided, and how additional information might increase their stress levels or influence their decision making and engagement in the NICU. Parents understood the well-intentioned efforts of staff to keep them (parents) informed and abreast about their baby's condition but experienced it in a manner that felt demotivating. They felt that in their endeavour to protect parents from hurt, staff denied them hope. Further, the use of medical jargon was a common concern among parents. This not only hindered their ability to communicate effectively with staff, but also intensified the sense of vulnerability they felt in the NICU environment.

"We had a couple of the consultants who who felt..that they wanted to tell us the condition of certainly Henry (Twin 2) *once Olly* (Twin 1*) had gone* [died] *… It was like the situation is dire. Then they would explain how awful it was for Henry and that would create a …. what I would describe afterwards as a man-made dip in the rollercoaster that we didn't need to have. There was enough of them happening. We were short of sleep. We would get calls most nights to go round. That was like this might be the end. We were pretty much on the edge all of the time…. I think because in a NICU you know you're expecting bad outcomes, or the healthcare professional* [Staff] *see bad outcomes so frequently and they have to be steeled to it and harden to it…. All these people trying to understand is trying to give information from positive intent but was*

lumping on more like avoiding us…. It was almost like you weren't allowed hope. Lumping on as much as possible of weight on us, so that we didn't get what would be seen as false hope because so many poor outcomes leave the NICU or patients don't leave them NICU and patient and parents and destroyed…." (Roy)

"They [Staff] need to understand that you know… you use these technical words, but…as with his doctor… But… we are not [medically] *qualified in that kind of... we don't know what this stuff means... So they should really help us make sure we understand everything…put into words that we understand, that we can comprehend. I feel like a lot they could have changed". (Mariam)*

4.2.2.2 INSENSITIVE AND DISRESPECTFUL BEHAVIOUR OF NICU STAFF

Parents reported not always receiving the respect and compassion they felt they required during their time in the NICU. Numerous instances were recounted where staff apparently showed a complete lack of sensitivity to the parent's circumstances, making disrespectful statements such as *leave him* (the baby) *alone* or *oh, she* (the baby) *is still here?* It appeared the parent's devastating loss was a routine event for the staff. Often, they did not seem to be mindful of their choice of words when conversing with parents. This was perceived as demonstrating a clear disregard for and insensitivity towards the situation.

"Two days before the surgery she had had another episode where she completely just went lifeless and they said that they need to check the pressures in the… to see if they're able to do surgery or not….The senior consultant… Yeah, I just I was sitting waiting for them to bring my daughter up from what they had just done, he came over and his exact words were…'The pressures are too high in her lungs, so she'll die'. Walked off.. he just he just walked off. I.. I.. I.. was by myself…I didn't know I. I just sat there because I I didn't even…." [field notes: participant crying inconsolably, but did not want to pause the interview when asked] *(Pearl)*

Many parents recounted instances of apparently disrespectful behaviour from the staff, which had adverse effects on them, including parents feeling devalued and worthless. One such consequence was experienced by Dolores, who is also a healthcare worker herself. She understood and acknowledged that the staff were very busy dealing with emergencies and focusing on babies with higher chances of survival. However, she felt neglected. Despite the decision not to resuscitate her baby after birth, she noticed a lack of communication about the plan of action and felt that her own condition was not being adequately monitored. Possibly because she was a nurse herself, she was expected to understand and accommodate more. This left her feeling insignificant and devalued.

> *"I felt like because my baby is not compatible for life, they actually neglected me… It's just that.. I'm also a patient, regardless of whatever I carry.." (Dolores)*

Instances of disrespectful behaviour also encompassed a lack of cultural sensitivity among the staff, as perceived by parents. A few mothers correlated this neglect and disregard as tied to their ethnicity.

> *"Like I feel like feel like if I had been white and middle class up classy then I would have got more support throughout my pregnancy and after… I do believe that my ethnicity had a..had some kind of effect on care. Maybe if my son was white and he was so cute.. blue eyes or something then he would have got more love and attention and care. It does make a difference". (Mariam)*

Communication barriers between parents and NICU staff further contributed to their feeling of being silenced, a topic we explored in the first theme. Lack of awareness about their *rights*, a perceived disadvantage due to lack of clinical background along with insensitive interactions with the staff, exacerbated the marginalisation experienced by parents.

4.2.2.3 INCONSISTENT COMMUNICATION

Inconsistent communication within the NICU emerged as a major stressor for parents, arising from staff rotation and shift changes. While primarily a procedural issue, it became more complicated when further affected by differing personal opinions of clinicians and their lack of understanding of the background of particular cases.

> *"The thing that was very difficult is we had a lot of different nurses because of this hand over in the shifts could not know the nurses. There was loads of nurses. It's, but then you get to know them. But the consultants all differed. So, we saw four consultants out of I think 6. And they all differed on their opinions". (Rose).*

Getting to know their baby, and knowing their movements and activities was as important for parents as provision of good medical care; it made them feel valued. Each shift change disrupted this personal connection, which parents found both disempowering and unnerving. This inconsistency was especially troubling given parents' limited involvement in their child's care, placing them consistently on the receiving end of communication. Moreover, staff often dismissed parent's opinions and disregarded their instincts, leading to discomfort among parents due to both the absence of background understanding and the lack of rapport.

> *"It's not something short… It's the level of communication certainly seems defunct. Let's hope it's the right word. It it seems… a bit contradicting each other all the time. So one nurse will be on doing one thing. Another one come and complete opposite and obviously. Where is.. I'm not saying they are not professionals and not doing their job. I think when they're dealing with your child, you certainly get the anxiety of why you done that and they're doing that and the doctor will do the same... come in and do something and then come in the next…three days later and do something else and you're a bit like, can you communicate me why the changes there? Because the communication is pretty limited when they communicate, is very much from the self-standpoint of... I'm the doctor. This is what I am doing..."(Steven)*

4.2.2.4 POSTIVE COMMUNICATION AND KINDNESS IN NICU- "BEAUTY IN ADVERSITY"

Communication and interpersonal relations with the NICU staff constituted a fundamental and critical part of the parents' experience in the NICU. As Clara said, "*I didn't enter a war ground. I tried to have a baby";* it is essential for parents to feel seen, valued, comforted, and supported.

While the overarching narrative was one of unpleasant experiences in terms of relationships and engagement with the staff, there were glimpses of *kindness* and *beauty in adversity.* Parents noted that even the smallest gestures from staff could significantly improve their experiences of loss and grief. They appreciated it when staff gave them their time and full attention, making them feel seen and heard. Regardless of the outcome, parents cherished the comforting words and acts of kindness shown to them, and these moments of kindness left a lasting impact on their journey through bereavement.

> *"You're working in neonatal unit. It's not all rosy. It's lovely when children walk out the door, but not all children do. And they say it all the time and… when they're in tears…you know, like the boys actually meant something to her. That's sort of people that you want to talk to…" (Peter)*

4.2.3 THEME 3 - SURVIVING GRIEF

The final theme of this section underscores the grieving journey that parents found themselves undertaking following the death of their baby. It illuminates their struggle to accept the new reality, the overwhelming presence of grief, and their efforts to navigate life while bearing the grief from the loss of their newborn baby. It is crucial to highlight that their grieving and bereavement journey was significantly influenced by their experience in the NICU, where they faced a loss of agency and experienced disempowerment. This theme is divided into three sub-themes, 1) The profound emotional impact of the baby's death and the evolution of grief, 2) Coping with grief and 3) Bereavement support. Through these sub-themes, I aim to encapsulate their efforts in traversing this new life terrain. In this journey parents unlearn and

relearn life, undergoing a transformation of self. This process of transformation is marked by the evolution of their grief. Parents traversed various phases from denial, to accepting their new reality of being a bereaved parent, to mourning and coping, and finally attempting to reconstruct their lives around their new-found identity.

4.2.3.1 PROFOUND EMOTIONAL IMPACT OF BABY'S DEATH AND EVOLUTION OF GRIEF

All parents depicted the death of their baby as an intensely emotional experience. Generally, mothers were more expressive about their emotional reactions to grief, while fathers shared minimal details. Mothers commonly experienced anger, shock, disbelief, and denial. Regardless of their baby's poor prognosis and condition, they struggled to process this news and expressed their resistance to accept this reality. They were unprepared for this outcome, and by maintaining hope throughout the NICU period, they didn't anticipate their baby's possible death.

> *"I just wanted to put some running shoes on and run away". (Anna).*

> *"I just didn't believe it wasn't possible to me like it didn't make sense. It didn't mean anything to me at the time because… those were just words like I didn't… it didn't mean anything, and it was all rushed…" (Mariam)*

Some mothers equated the feeling of losing their child to a sense of self-loss, either not wanting to live anymore or feeling as though they had died themselves. Overall, all mothers felt a part of themselves was missing and lost forever.

> *"The first morning I woke up after Olly died, these words came into my head and I said to myself, oh my god, I'm alive. It was like I died. I didn't think I was alive* [field notes: here participant talks in a very slow pace, as if she is reliving the moment]*. During the night, it must have been, you know, that's when I woke up and I realized I was alive and I was in the room…" (Clara)*

Holding their baby during and after their death was deeply meaningful for all parents, particularly as their grief evolved over time. Although it did not provide closure, it brought them closer to the truth of their baby's death as well to their baby. A few mothers revealed they did not hold their baby during their final moments, either because of guilt for not being able to protect their baby or fear, and this led to immense regret and emotional turmoil. These mothers wished they could rewind time and use that opportunity to bond with their baby or that they had received better guidance at the time.

> *"I let her die on my partner because I didn't feel like I deserved that". (Sarah)*

A similar experience was shared by Anna who was not present at the time of her baby's death, which caused her immense guilt. She remembered her son's appearance and the darkening of his skin. She shared how she could not look at him because of a change in his appearance. She continued to live with the regret and disbelief that she could not look at her own child and was *frightened* of his appearance.

> *"I went to bed. It was like a family parents' unit. I was just exhausted. I went to bed. And the nurse was looking for me at 7:00 o'clock. She came down to the room. And she said Freddy's deteriorating. And he died at 20 to 10 (9:40am). But I wasn't with him. I was too frightened. My husband was there".* [field notes: describing the events that happened when her son died, the participant cried a lot. She cried not only because she was telling me about the time her first born son died, but more importantly because she wasn't there with him when he died. That is what has taken precedence in her memory, the regret and guilt that she wasn't there with her son at the time of his death] *(Anna)*

Some mothers believed that their experience was more challenging because, unlike a miscarriage or stillbirth, their baby was born, had a life (albeit small) and an identity. As parents, they had spent time, bonded, and created memories before he/she was *taken away.* Despite their time in the NICU, they felt unprepared for their baby's death, which they attributed

to societal silence around newborn death. In many cultures, newborn death is a taboo subject, often concealed from any discussion. This cultural silence impacts a mother's grieving journey, especially since she is expected to move on quickly.

> *"I think it's just not talked about, especially a child's death is not talked about at all because we're so used to adults' death, so we're not used to children's death…talking about it, but specifically in our* [British-Pakistani] *cultures we don't talk about death as it is, but when it's a baby and innocent baby no one knows how to deal with that. Just have to do this as you can really got no choice". (Mariam)*

Living through their newborn baby's death and grief started a process of realisation and introspection for parents. In an attempt to reform, reorganise and restore their lives, parents engaged in different activities. These activities were not merely a distraction and an attempt to move-on with their lives but more importantly gave them a sense of purpose to honour their child's memory and life. Sarah was now studying to become a lawyer; Clara was an advocate on family integrated care and communication in the NICU and Steven established a charity organisation to raise funds for supporting neonatal care of premature babies. As life moved on, parents feared that their child would be forgotten by the world. They were anxious about preserving the existence of their child's memory, not wanting it to be confined to the NICU, where their baby *lived and died.*

> *"My biggest fear is that he's gone and forgotten. He's only done three weeks. Nobody got any memory of him. He hasn't set footprint on the ground… What what is it that keeps him alive? What is it that keeps him in? You know, not just in Clara and I's heart, but you know…"(Roy)*

The overwhelming nature of grief continued to affect most parents, regardless of the time elapsed since bereavement. While some parents reported a lessening impact with time, others experienced a profound shift in identity and perspective. Some parents gained a newfound respect for life, but also acknowledged they thought they could never be *fully happy* again in

life. Over time as they came closer to accepting the indefinite nature of their loss, parents learnt to coexist with their grief, as it became an integral part of their life.

> *"At the minute, we're not we're not crippled anymore. We're not crippled by the pain anymore".* [field notes: there was a long pause here. It seemed as though participant was examining her stage of grief in this moment] *(Sarah)*

> *"I don't think it changes it just go in a circle. Then intensity changes but depends on how… it occur on that particular moment. Depends on what memory that comes back to you. So that's how I looked at it, it never, it never goes away, it just becomes lighter at some days. Some days it's too much to bear that you just have to shut down for minute and then go back again". (Dolores)*

4.2.3.2 COPING WITH GRIEF

Most parents began to cope with grief even before their baby's death. This often accompanied the parents' anticipatory grief, particularly when spending time with the baby just prior to death (unless circumstances, such as sudden death, did not permit) and in some cases, prior to the birth of the baby.

> *"I had my my epidural and just lay there crying and it was horrible …[addresses the interviewer] because they were still moving"* [field notes: this conversation was emotionally intense with both participant and interviewer shared a recognition of trauma experienced by her. The participant reflected on that moment as she awaited the birth and death of her boys.] *(Clara).*

Every parent had their unique timeline and coping mechanisms, which varied based on available support resources. What some parents found supportive, others saw as barriers, causing a struggle as they sought meaning in life after loss.

Generally, mothers found it comforting when they shared their grief with others. Speaking about their loss felt therapeutic, allowing them to ensure their child's memory lived on.

Wherever possible they talked about their baby, included their names in prayers, professed their love, and displayed their pictures at home. While most parents had supporting spousal relationships, they reported experiencing grief differently to their spouses. Women often expressed their loss and emotions with their families, when possible, but this was frequently accompanied by guilt as they felt they were inflicting further pain on their loved ones.

> *"I feel guilty for putting a burden on them… making them feel sad and low and I just feel like it's been a year". (Dolores)*

Family played a crucial role in helping parents cope, but not all parents had the opportunity or space allowed to talk and mourn. As discussed in the previous section, cultural restrictions sometimes imposed strict societal expectations on women. These expectations urged them to conform to a 'correct manner' of grieving, which involved moving on quickly, suppressing their emotions, and inhibiting their ability to advocate for themselves. During this process of coping and societal adjustment, mothers often found themselves feeling alienated, along with their grief.

> *"He was in my arms when he passed away. My dad said what you're holding him for. He's gone now. Just leave him. So, I just left it there. And I went home to my mum and dad's house, my husband went home to his brother's house and we were separate that night. And then obviously. Well it is.. it is just like really hard, because obviously it's the culture rather than the actual religion itself, and it's just… I feel like I was robbed in a way, but then we didn't know. We just all assumed that's that must be the right thing…*[but] *now* [feels like] *it was brushed under the carpet… It was in a way,* [he] *is out of sight, out of mind". (Jannat)*

Lack of recognition of parent's grief extended beyond cultural restrictions. Parents shared their accounts of feeling unrecognised, when they needed the space to talk about their baby's birth and death but often found how others were unwilling to engage in such conversations. Peter

described a similar engagement with his mother shortly after the twins died, where he desired this acknowledgement, but did not receive.

> *"And when we went home, my mom said, well, never say never...My mum! you've just lost two grandchildren, that in space of a month and you are on about me, if I should be trying again? I left him like 15 minutes ago and you went about trying to get in?" (Peter)*

> *"What people don't understand is you can still talk about it and move on". (Jannat)*

The perceived lack of recognition impacted parent's grief. Especially mothers, who wanted to talk about their grief and share their emotions felt they were not adequately supported. Their desired to talk about their loss and feel that their agony and hurt was shared by others. It was important for them to feel they were not alone in their grief and that their baby *meant something* to others as well.

> *"I remember thinking everybody's thinking it's just a little baby… And I wanted everybody to cry, the whole world… It's like it didn't matter. Like he was here for a few days until he wasnt.. like he was insignificant. I remember thinking why isn't everybody hurt? Why those people laughing. It was absolutely monumental that everybody wasn't sad like me….. I wanted everybody to sit down and cry…" (Anna)*

Often in response to a lack of recognition, parents immersed themselves in organising a funeral for their baby. This acted as a coping mechanism, allowing them to share their grief and love for their baby with family and friends, celebrate the short life their child lived, and aim to provide a memorable farewell. It was a final opportunity to do something momentous for their baby as a mother, a role they felt they had not been able to fulfil adequately.

> *"I suppose grief is the … the flip side of love is in. It's the same coin issues the other half. So, it was just shared. Wanted to share the love. It's not. It's not. Grief doesn't exist without love, so it's just sharing the love and I wanted a celebration of the fact*

that we even got pregnant, had a baby. He was beautiful. He had the most beautiful little face… I just wanted that fun element and we used to sing…. I can't do anything about him being dead, but we must find joy in in his life and in the fact that I love him…" (Clara)

Getting pregnant or being a parent to other children was a common pathway that parents used for coping with their grief. It provided them with a sense of purpose and meaning. Having older children at home to care for and look after meant that parents had little time to slow down. Their focus during the NICU days and afterward was ensuring they supported their other children and remained fully present for them. For first-time parents, this approach of planning a subsequent pregnancy sometimes served as the only way they could navigate through their grief.

"I got pregnant about five weeks after because a lot of people said to us, the only way you're... the only... I, I seeked out and I sort of spoke to mums that lost their babies and I said how on Earth do you get through this because I'm not seeing any sort of light at all and it's just getting harder and harder, and they said the only time I felt any sort of relief from that pain was when I held a living baby in my arms… and I said, right, well, I think that's the only thing that's left… I have tried counselling, antidepressants and it… everything was just getting worse. My partner was worryingly worse. And actually, I was worried for his health. So I thought, you know we, we've got to, we've got to have…something to live for..really, and especially for him". (Sarah)

4.2.3.3 NEEDED TO BE HEARD- BEREAVEMENT SUPPORT

Grieving was an intensely isolating period for all parents. After the initial mourning period, during which they were surrounded by family and relatives offering support and their time, they returned to a new normality that felt daunting. During this time, they found themselves struggling and feeling desolate, unable to come to terms with their new reality and desperately seeking support. However, there was a prevalent sense of dissatisfaction among almost all

parents regarding the bereavement support provided by the NHS. While they had access to, or were offered counselling support at some point, it became evident from their narratives that parents did not feel fully supported or adequately acknowledged in their loss by the hospital staff, including nurses, doctors, psychologists, or counsellors. For parents who experienced bereavement during the COVID-19 pandemic, counselling was offered online, while for others, it was in-person. Regardless of the mode of support, parents did not find counselling to be helpful. Some mothers felt abandoned as they perceived a lack of active efforts from the system (NHS) to assist them.

> *"You know mothers are suffering in silence and you know for me…I live my life as if you know…I call it a life sentence…It's a life sentence... this June will be 2 years and it's all… Where do we go? Wait, where do we go? You can call it* [counselling services], *but if you're not hearing anything more, if you call once, and someone just gives up on you because they called it, you didn't answer, I just think the mental state of parents during those times is … is a little bit neglected to be honest with you. We're not saying come and hold our hand and every little thing you should be… you know it's just, it's just not there…" (Pearl)*

A prevailing sentiment among parents was a feeling of being disrespected, with their grief not being taken *seriously* by the counsellors. Although shared mutually among parents, this sentiment was particularly strong among mothers who desired to openly express their grief. They did not seek prescriptive sessions or advice on how to move on. Instead, they longed for someone to simply listen as they navigated through their trauma, shared their dreams for their child and family, and mourned the profound loss they experienced. The interviews provided a valuable outlet for mothers to share their stories, a platform they felt they had often been deprived of, regardless of the time since their bereavement. The feeling of disrespect among parents also stemmed from being counselled by individuals who had not personally experienced the same level of emotional trauma.

"It's hard to... It's hard to be football coach if you don't know how to play football. I think it's quite odd to... even as bereaved parents, want to listen to someone that's never been through it before because it might sound quite arrogant to say, but because obviously…you're quite angry and… and you're hurting. You don't really want to listen to someone that's…talking to you about what they've been trained". (Peter)

All parents were offered memory-making opportunities after their baby had died in the NICU. These included taking pictures with the baby, creating hand and footprints, and preserving a few locks of their hair. Parents expressed appreciation for these gestures as they provided something tangible to treasure and hold onto. However, these offerings were not sufficient for parents to feel that they had the support they needed during what was experienced to be the most traumatic period of their lives.

"We did that the first day and the nurse was very good at arranging it and it you know… there, seemed to be a well-practiced routine, but it felt really caring a... Like quite practice routine… But certainly, at some point I would have liked to have got upset and talked about what my dreams for him had been. What I did think he was capable of? What I think Henry will miss out from not having a twin like.. talk about…okay.." (Roy)

Mothers also highlighted the insufficient support available for fathers. Societal expectations that men should be strong, composed, and the providers, often hindered their ability to seek support, and many men found it difficult to advocate for themselves. Out of the four fathers interviewed in this study, only one expressed his need to express himself emotionally, while the others refrained from doing so and felt discomfort when conversations became emotional rather than factual.

"There's not much help for dads. It's like it's all about mum… And I think that dads need just as much support sometimes if not more… because they're always meant to be the strong one. They've always meant to be the one that picks up the pieces. That day he lost children the same as what I did. I do think there needs to be… Obviously I got the

phone calls… For some reason it's always aimed at phoning mum. And sometimes it does need to…It should be aimed at both. It shouldn't be just...they take my word for it. They should be phoning Peter to say…Do you need any help? Do you need anything? Do you need support? because it's not… It's both of us, not just one. That is the only thing I think that needs to...They need to put more emphasis on the fact that it's both parents, not just mum". (Jane)

Finally, a key aspect of support that retrospectively most parents expected but did not receive was the administrative task of registering their baby's death. The lack of information and support on the matter was puzzling for many. The experience was made more traumatic by the fact that parents had to register both, the birth and death of the baby at the same time. Although they understood it was a *task that had to be done*, the irony of situation made it an even more distressing experience for the grieving parents.

"No one is gone through and already prepared me for just... like how bizarre and unfair and obscene having a registered death at the same time as you register Olly's birth". (Roy)

In line with their need to share and in the absence of adequate institutional support, women exhibited greater initiative in seeking help for themselves, such as joining bereavement support groups. This may be attributed to the fact that as they spoke about their grief, they gained a deeper understanding of their own needs and felt more comfortable reaching out for assistance. Additionally, all mothers expressed a strong sense of empathy towards others who had experienced the loss of a loved one, and they had a desire to support those in similar situations. This empathy and desire to help others were prominent reasons why they wanted to participate in the study. They viewed it as an opportunity to advocate for other parents and women who may face a similar fate, while also making a meaningful contribution towards improving the system.

4.3 THE PHENOMENON OF LIVING THROUGH A LOSS OF AGENCY

Parents experienced NICU as a disempowering space, where they often found themselves living through a loss of agency. The combination of their child's critical condition, the highly intensive and technical environment and poorly babies, along with power imbalances and what felt like dysfunctional relationships with medical staff, contributed to the overall incapacitating experience. Grieving was an intensely isolating period for all parents. The transition from becoming a parent to a newborn baby to the baby's death was transformative for them as an individual, but grief was constant and persistent. They found themselves struggling and feeling desolate, unable to come to terms with their new reality and desperately seeking support. However, there was prevailing sentiment of feeling disrespected, with their grief not being taken seriously by the counsellors. Consequently, parents found themselves silenced, voiceless, isolated, and without an advocate.

Living through a loss of agency and standing through powerlessness was the phenomenon that unfolded from parents' lived experience of newborn death. It was not an absolute moment that led to defining this phenomenon, but a gradual experience through which parents lived every day in the NICU. What was evident from their narratives was that their newborn baby's death was a life changing and an extremely challenging experience. Despite being an event, it was a journey where they found their old selves unfolding into a new reality. As they transitioned from being a parent of a sick baby in the NICU to his/her death, parents experienced a transformation of self, their "*being-in-the-world*", that was different from their previously established identity. This change was not always realised immediately and for most it was a result of reflection of their lived experience of the NICU and their newborn baby's death. The time span varied. For some, the realisation of this transformation was unsettling and for some the process was still underway. Nonetheless, it added to their guilt and feeling of failure as a parent.

4.4 CONCLUSION

The exploration of parental lived experiences of newborn death revealed three broad themes, 1- to be a parent in the NICU; 2- relational and structural processes in NICU; and 3- surviving grief. This chapter presented these main themes and emerging sub-themes and the interpreted phenomenon. It provided an insight into the lifeworld of parents as they grieve their newborn baby's death and reorganise their lives.

Despite the time since their newborn baby's death, loss of agency continued to be the predominant phenomenon in parent's lives. While some continued to live through it, standing through powerlessness, for others it became their life's purpose not to relinquish control over their lives again. It manifested in different ways, whether it was advocating for their partners or future children to get the medical care and the support they needed or standing up to their families. Nonetheless, it was heart-warming to see how despite the grief and anger, there was an overwhelming presence of compassion in each of them. Most significantly, for all the parents, being a part of the study was an important step towards helping someone else not experience the same disempowerment. It was an opportunity of sharing their story as they still grieved, in the hope that they may be able to influence and manoeuvre someone else's narrative by raising awareness around parental experience of newborn death in the NICU.

I will conclude this chapter by sharing a poem penned by Anna, one of the participants (with her prior consent) that captures and conveys the essence of the phenomenon; of loss of agency and standing through powerlessness as parents lived through their newborn baby's death.

NEVER

I never would have left you son, I longed to be with you

Whatever life had thrown at me I'd have stuck with you

I never would have left you to grow up without me

Through sleepless nights and tantrums, dry tears and bathe cut knees

I never would have left you with problems to overcome

No watchful eye, no good advice from your ever-loving mum.

And if God had called me to him, If you'd lived and I had died

My spirit would watch over you, I'd never leave your side

CHAPTER 5- "*AT LEAST YOU HAVE DONE SOMETHING FOR THAT FAMILY*": STAFF'S LIVED EXPERIENCE OF NEWBORN DEATH

5.0 INTRODUCTION

This chapter will explore the NICU staffs' experiences of newborn death and supporting parents through bereavement and the NICU processes. The descriptions of lived experiences will be presented along with a deeper analysis of the data.

5.1 SECTION ONE – PARTICIPANTS

Five nurses and three doctors were recruited from the NICUs of three tertiary level hospitals in the UK. All interviews, except one, were conducted virtually on Microsoft Teams, in accordance with participant preferences. Among the five nurses, the years of experience in the NICU ranged from 7 to 20 years, while for doctors it ranged between 3 to 13 years. Co-incidentally all participants were female. Specific details of ethnicity, background as well as hospital names have not been shared and pseudonyms agnostic to ethnicity have been given to maintain participants' anonymity and confidentiality.

5.2 SECTION TWO- THEMES AND INTERPRETATION

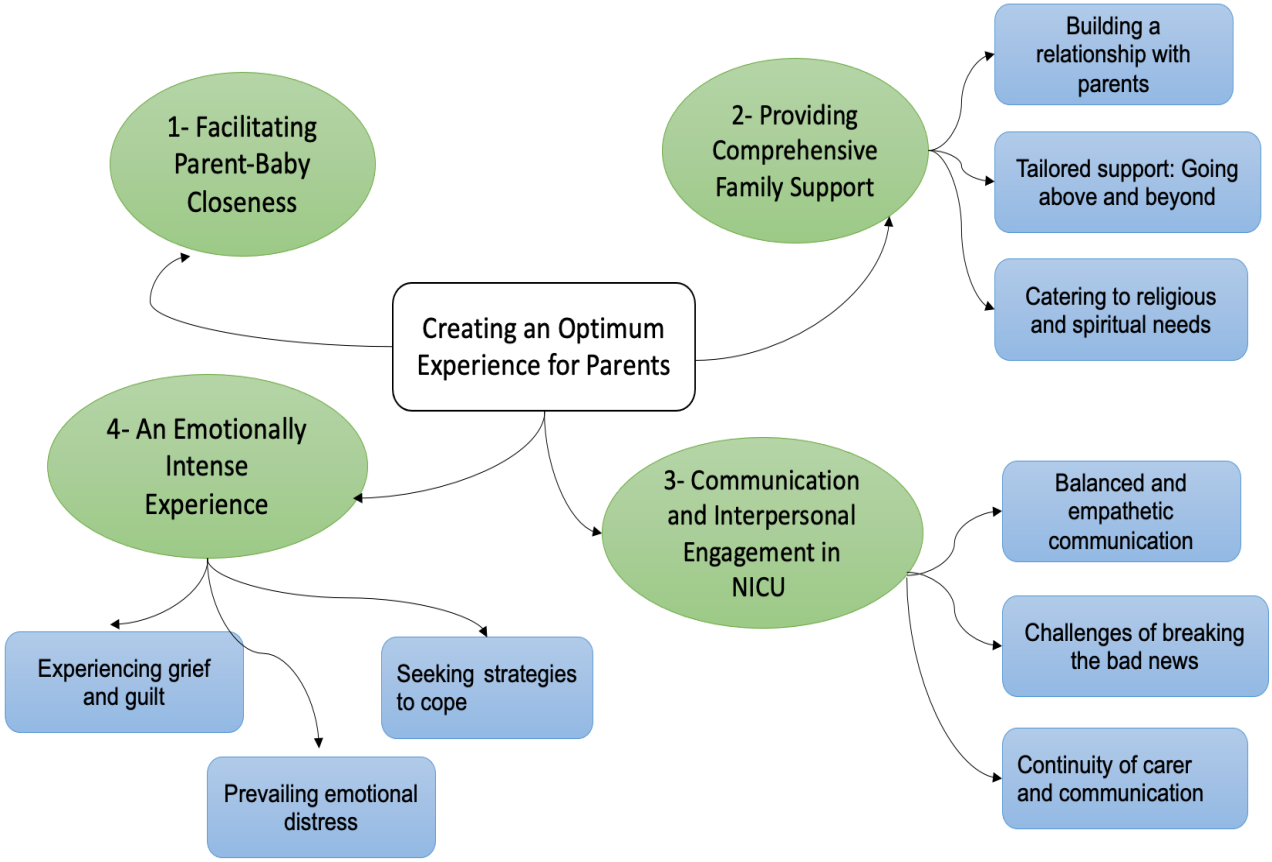
Lived experience of NICU staff appeared to be influenced by whether the newborn baby's death was "*expected"* (gradual decline) or "*unexpected"* (sudden). By *expected* deaths staff described being aware of the eventuality of outcome due to their clinical experience, feeling

mentally prepared for the same as well as preparing parents in time for the feared outcome. Whereas, with *unexpected* deaths where the babies deteriorated suddenly, they reported feeling caught off-guard, not allowing them time to prepare themselves as well as the parents.

> *it's different because in the HIE, they know it from the very beginning. From the first day, second day third day there is no improvement and they're updated daily with they can feel the baby is not moving they're not like holding their hands. No gross reflexes Moro reflex or movement and frequent like suctioning so they know that they know that their baby is not well so by day by day they are like preparing themselves to the worst things happen you know after the rewarming…..*[whereas] *in premature they just like, they know their baby's small but then they will know because as of now 23 weaker can survive.. so they have hope… and they believe in miracle… maybe because they heard or they have seen some in the newspaper that.. so many small babies survive this time yeah so, it's different approach really for the small one...* (Nurse Lauren)

This temporality influenced the overall lived experience of staff. Interpretive analysis of interview data revealed the phenomenon of, 'Creating an optimal experience for parents'. Four themes helped build further understanding of this: 1) Facilitating parent- baby closeness; 2) Providing comprehensive support to the family; 3) Communication and inter-personal engagement in the NICU; and 4) An emotionally intense experience.

Figure 5- Diagrammatic representation of thematic analysis of NICU staff's lived experiences



5.2.1 THEME 1- FACILITATING PARENT-BABY CLOSENESS

A newborn baby's admission to the NICU is characterised by a painful separation of parents from their baby. To minimise the impact of this separation, NICU staff endeavoured to promote physical closeness of parents with their baby and created time and space for parents to be a parent to their baby. This was often the first and most important step acknowledged by staff, towards creating an optimal experience for parents, given the adversity of the situation. It is important to note, that this theme, albeit a prominent one, emerged primarily from the narratives of nurses, perhaps due to the nature of their engagement with each baby and their family.

All the nurses interviewed recognised the need for physical closeness between parents and the baby. Irrespective of the time spent in the NICU, nurses tried to encourage parents to spend time with their baby by bringing them into the NICU. This encouragement was aimed at facilitating physical and emotional bonding of parents and their baby.

> *"So usually I asked them to you know sit next to the incubator and hold the baby..or hold or cuddle, even* [if] *the baby's very sick I offer them… before also and then after* [death] *as well.. but then I mean not really like cuddle if the baby's very sick so just like open the incubator and put their hand there … so they can feel the skin of the baby or talk to the baby and yeah sometimes I read the book like we have a book given to the baby which says I love you very much…they can read that.. sometimes they can sing, they can talk, and they can go for the baby, hold it and then you... you give them some space…"* (Nurse Lauren)

Most nurses echoed this idea of facilitating parent-baby closeness as their priority. Creating time and space to support parents in 'being a parent to their baby' was crucial for them. For babies where they expected the outcome of death, it was even more important to create opportunities such as for parents to wash and change the baby.

> *"…whatever the parents wants to do, I don't really care what…as long as.. I can see parents having time with the baby, bonding with the baby, grieving with the baby .. You know, try to support them as much as possible. I think for me that's like more important than anything else… you try to make the baby comfortable as possible, try to change the nappy with the parents. Wash the baby with the parents... give the baby to do skin to skin with them.."* (Nurse Anne)

Given the baby's critical condition, parents are not always comfortable and confident in establishing physical contact. They are afraid and hesitant to hold the baby or sometimes even touch. In such circumstances, nurses supported them to overcome those fears and bridge the

gap by gently directing them closer to the baby. They believed parents feel supported when they see a nurse caring for them and involving them in baby's care.

> *"No, you hold their hand and touch the baby and then... they are less afraid and can hold the baby. It's just that in the first they are afraid to touch the baby or hold. So, I think…even if the baby is so sick I think the touch is really important and bringing them. You help them to face that, accept that and touch that.. they will become connected* [with] *the baby..* " (Nurse Lauren)

The hesitation of parents towards proximity also extended beyond baby's life. There were examples shared by nurses where parents did not want to be with the baby during and after baby's death. While they completely respected parents' wishes, they also wanted to ensure these choices did not come with any long-term regrets, further complicating their grief. Therefore, often at the risk of parent's disapproval, nurses softly nudged them to consider spending the limited time they had with their baby.

> *"Yeah, it was fairly recent this happened... baby was on a ventilator so the parents agreed that we could take the baby off a ventilator, but they didn't want to see the baby being taken off. They basically said okay, we'll leave now and will wait in the parents room. And every now and then a relative would come and say has it happened yet, and we'd say no. And it felt…*[field notes: she takes a moment of pause here as though she is reflecting on the day and reminding herself of the emotions she felt]… *I don't know it was very different and I think at the time… I felt sad because I thought I hope that this is actually what they want in the sense that they really don't want to be there... after baby passed away we really kind of… not encourage but we said, you know, do you want to spend time with the baby and you could make memories and actually they've decided yes they did. So, they spent time with the baby afterwards, which I think was really valuable for them…"* (Nurse Savy)

A similar experience was shared by another nurse regarding the memory-making process commonly followed in most NICUs in the NHS. Memory-making is not merely about taking a few photographs or baby's hand/foot imprints. It is memorabilia of the baby's existence, for parents to look back at, to value and hold on to. Sometimes in the moment of intense emotions and grief parents refused having anything done. However, as a nurse she understood the complexity of the situation and therefore, decided to go ahead, and potentially, again helping parents avoid a long-term regret. She believed, in that instance having gone against their wishes was for their own benefit.

> "[We have] *memory boxes where we take her little bit of hair from the baby and like an imprint of their … feet and usually the nurses, we do that.. I tried to offer it to do it with mummy. She didn't want to…but I did it anyway because I think in the future they will want to have something from the baby. So we do it and sometimes they don't pick it up. But there after a couple of years they call and ask whether we have the box or not. So I think it's something that's very valuable for them".* (Nurse Anne)

The nature of baby's death (*expected* or *unexpected)* had a significant role to play in staff's efforts to maximise parents' time with their baby. In an *unexpected* death, it was harder for them because the parents had no time to prepare and were often not present with the baby. Conversely, in *expected* deaths, they were better placed to facilitate the process of bonding and spending time with the baby making memories.

> *"When you have an expected one* [death]*, it's like you have time to do things..like you give the baby for cuddles..even if the baby is ventilated and has a lot of things..or if the grandparents want to come in and see the baby in...to wash the baby, change the nappy, things like that make the parents bond with the baby that's…it's beautiful. It's beautiful to do it in a way because you are giving the opportunity for those parents.... when you have that that time because time here is just precious… it's rewarding in a*

way, because I mean as hard as it is at least you have done something for that family." (Nurse Anne)

The COVID19 pandemic brought challenges, especially in staff's efforts to ensure physical closeness. One of the nurses reported how they felt *lucky* that the restrictions were imposed for a short period of time. This expression reiterates the value that nurses gave to enabling parent-baby closeness, and how an absence of that was experienced with difficulty.

"Covid.. it's been particularly difficult…made bereavement very difficult….during the first lockdown last year where we just had one parent that was allowed in every day, and but then the parents had to swap. If so, say Dad wanted to come for their mum couldn't visit. Luckily that only lasted for a month, and we did have a bereavement in that stage. And then the parents were allowed in together, obviously. And but no extended family was. That was awful." (Nurse Agnes)

Facilitating physical closeness was recognised as a critical aspect of care and support provided by the nurses in the NICU. Not only was it regarded as vital for parents as they lived through their grief, but it was also important for nurses to find meaning in their role. It brought them solace and comfort and gave them the strength to carry on.

"Yeah, I mean now…sometimes when I finish…whenever I had these, expected [deaths]*, when I finish my shift, in spite of everything I feel..that the baby at least had the parents with him and then the parents had opportunity to hold their babies for as long as they wanted to hold the baby".* [field notes: there is a sense of calmness and gratitude in the nurses tone and body language because she was able to facilitate parent-baby closeness at the time of baby's death]. (Nurse Anne)

"I and my colleagues really tried the best for the baby and the parents. And even though it's a sad situation, we can still try and find some positives…You know his life…even though sadly the baby didn't.. you know… during the time that the baby was alive to

be able to show the parents' love and care for their baby, and that baby means something and is important.. is really special". (Nurse Savy)

5.2.2 THEME 2 - PROVIDING COMPREHENSIVE FAMILY SUPPORT

The second theme is about NICU staff's efforts to provide comprehensive support to parents and families as a critical part of NICU care. The support ranged from building a relationship with parents, understanding their needs, and tending to those needs empathetically. It was a priority for the staff to bring in as much comfort to the parents as possible in the emotionally draining NICU environment. Sometimes it also entailed going above and beyond their usual duties. Supporting parents was an integral part of staff's lived experience, as it brought them closer to their goal of creating an optimal experience for parents.

5.2.2.1 BUILDING A RELATIONSHIP WITH PARENTS

NICU environment is challenging for both staff and parents. While caring for a dying newborn is not easy, parents undergo an emotionally turbulent journey whereby empathy and compassion from staff are essential. Specifically, nurses who spend longer duration with parents were often a part of their emotional journey. They witnessed the turbulence that parents go through first-hand. They also acknowledged the hope parents hold on to. In trying to support parents through this experience, NICU staff shared how they try and build a relationship with them, which is necessary to gain their trust and work collaboratively.

"I think [in] *NICU you form more of a relationship with the parents rather than.. of course the baby is there but the baby is not talking yet so the parents are the advocates for them".* (Doctor Kristy)

"When you're at cot-side for 12 hours.. and if you've got a sick baby, the parents are normally there for that length of time as well… You see them cling on to the smallest of hope that are… you're the ones that are talking to them and be like well, how did you get the name and stuff like that just these little conversations. So, you build up this

relationship very quickly with the parents that you've got in front of you because you're next to them for this whole length of time, whereas the doctors are coming in perhaps every hour. But it's the nurses that have got their relationship with them parents and who know that baby…" (Nurse Agnes)

Most nurses interviewed, believed that parents appreciate when they feel they are being listened to. Once trust is established, parents also recognise the efforts of staff and feel comforted in the care and support provided to them.

"Parents aren't expecting you…to come up with the right things. They just want you to listen and the dad actually said to me when I was going home, he said… I'll have to remember that you're human and that you have a life to go back to…And I felt really touched that in such an awful time he…in this all-consuming time his baby he said that and… even the mum during this time she said oh you need to you need to go through your lunch break… And it was like wow, like this mum is going through this like unimaginable pain and she's thinking of me and that I need to eat… It was really touching". (Nurse Savy)

In *expected* cases, staff explained that it was relatively easier to develop a bond and understanding with parents as they would spend more time together and were able to build rapport. Having that connection further helped them in navigating difficult situations and working collaboratively with parents.

"I think that's because from the beginning they knew and we had quite long time…you know to get that bond with the family, and they started trusting as they understood that it's not in our hand, we cannot do anything more than that and the more we prolong their life, it's more torture than support. So, you know, they were with us, it's like a team. So, this is the family who has prepared kind of fully". (Nurse Naomi)

Alternatively, in scenarios where staff did not get adequate time to prepare parents, they were caught off-guard. In many such instances, parents took time to accept the reality and

sometimes their anger was channelled towards the clinical team. It was often nurses who bore the brunt because they spent the most time with the baby and its parents. They understood the complexity of the situation and how in the absence of rapport and trust, parents may feel they are not supported.

> *"We didn't get time to prepare the family….. We gave a grim picture to this family…and we asked them what their wishes were, so Dad said he wanted… He was very angry…as if it's my fault.....but I knew they were in, they are very stressed so I didn't take any of these things personally, but I was purposely standing like a bit away from him so that because his posture was kind of aggressive and I was worried that he might lose control and he might do something so it was a bit scary, but we don't want him to [be] left alone either, so we just we just…I just standing back with good distance so that he can't reach me in case if he get very angry".* (Nurse Naomi)

There were other foundational challenges in building a relationship with parents. One such factor was the impact of ethnicity that brought along language and cultural barriers. For parents whose first language was not English, it was a challenge to communicate with the staff. This affected staff's ability to establish a rapport with parents and have open channels of communication, further impacting their ability to understand parental needs.

> *"They were South Asian parents and they had four girls and they're all in their teens. And this was a male boy obviously was much wanted and he had a lot of problems in this baby was too small and so this mum is not very talkative and obviously there is a language barrier, but I did speak in [a common language] and try to get on board but they are… it's very hard to reach them. And you talk to them, they will nod. You don't get much back from the mother, so. It's very tricky".* (Doctor Kristy)

5.2.2.2 TAILORED SUPPORT: GOING ABOVE AND BEYOND

Staff reported that they do not only care for the babies, but they also care for the baby's parents. This was particularly true of nurses, who are often the first and main point of contact for distressed parents. The support they provided was wide-ranging and mostly in response to what the family needed at that time. As the nurse below shared, their role was often cross-cutting through a variety of roles.

> *"Sometimes it feels like as a nurse we are everything.. we are like counsellors. Sometimes I feel like you know doctor as well, multidisciplinary, cleaners just general bit of everything up and there's so much to the day and it's family centered care. So we're not just caring for the baby were caring for the family as a whole".* (Nurse Savy)

There were moments where parents' needs were not aligned with what the staff wanted, or thought was the best way forward. Despite the differences, all participants interviewed described the importance of respecting parent's wishes and keeping their personal opinions and emotions separate.

> *"And that family didn't want to see the baby at all.. so we were calling the parents saying do you want to come because then she's going…and they were like no, no, no, we don't want to see the baby, so that's, at the end it was me and the other nurse we are holding the baby while she was dying* [field notes: she is emotional and still seemed to be in disbelief. It appeared that she felt sorry for the baby but also found it very difficult to hold her as she was dying]*… I cannot believe that they don't want to see the baby or they want to, but at the end of the day, you know their grief. I cannot imagine what it is, and people grieve differently so. As nurses we need to really empathize with them"* (Nurse Anne)

Throughout the conversations, staff acknowledged the importance of providing tailored support to parents. A precursor to individualised and tailored care was understanding what

parents need and while all participants acknowledged the importance of this, only one explicitly talked about specifically asking parents what they needed.

> *"I always start with do you need like what.. Who would you want for your support? because not everyone wants grandparents.. Why would you offer that?"* (Nurse Agnes)

Even during end-of-life care, each parent has their own needs and wishes. It could range from having extended family visit the baby in NICU or taking the baby out of the hospital. All the staff expressed the view that it was gratifying if they were able to meet those needs within the structural constraints, they sometimes operated in.

> *"It was not in his best interest, and we had to get the parents on board. Luckily even though they first went through denial in the first session, but they quickly came around and I think they realise that… there was no way forward for him, and his care was withdrawn in a garden in* [hospital]*. I was so glad that happened but in a way… Yeah, I, I think the parents were, mum was very keen on getting him outside in the fresh air with the birds singing..she just wanted that experience for him. I was happy that it was provided for them in a very controlled way".* (Doctor Kristy)

Constraints brought in by the institution sometimes restricted the staff in trying to address parental needs. In the quotation below, the nurse advocates for parents to have more control over their baby's end of life care and while the facilitating structures are often in place, it was the policy restrictions that denied staff such opportunities.

> *"What I would like to see… is for the parents to have more of a control over what happens to their baby after it's died maybe… I think when it's been requested… a lot of people have been shocked about it, but for some parents… they need to take that baby home to maybe integrate it into the family…and it's just getting the equipment in place to do it… and I don't think it's I don't think every family would want it, but I think it's saying we should be offering the families the choice of where they want, the way they want it done. We've got gardens in the hospital that we can use. We've got* [names

the hospice]*. Do they want to enter? And* [the hospice] *have got a lovely garden, you know, do we allow them to go home and do it that way? I think the parents need to have more choices".* (Nurse Agnes)

One of the senior nurses interviewed noted the importance of advance planning in providing tailored support to parents. She noted how in cases where she has the time to prepare herself and parents for death (*expected*), advance planning allows her to cater to all their needs and provide the best possible support to parents. It is something that brings her comfort and she feels that it enables her to be better at her job.

"So when you come yourself…organize your work like get your break on time before they [parents] *will come…because I think you need to prepare because looking after this.. so many things will happen you might ignore the parents, you might ignore their if you're busy in doing some things you know, either you can ignore their feelings* [or] *you can ignore talking to them. So, if you are prepared, and know your allocation…organize your work and plan about how are you going to assist or help this parents emotionally, psychologically and you know being there with them at the first few minutes…"* (Nurse Lauren)

Staff described how going an extra mile with small gestures and adding a personal touch sometimes meant the world to parents. Treating their baby like an individual with his/her unique identity was immeasurably important as it had the potential to make them forget about their challenges for a short period of time. Having a positive NICU environment was significant in building a supportive atmosphere.

"We lay our babies on quilts, and we all make a big fuss about getting the best quilts for our babies so that they look really nice so that when parents come and see them in morning they know how much we've cared for their babies. So, I found a quilt that had rockets on it...moon and it had stars and everything. So, dad came to see me at 6:00 o'clock in the morning. We hadn't had a particularly good night.. the baby wasn't

responding to any treatment.. he said oh how did baby boy do last night? And I was just like we've been to the moon. And I didn't tell him anything about what my nursing had done… [field notes: Participant tearing up while narrating this experience] *we made a big story that we've been to the moon, and we'd flown in a rocket and we'd walked out in our moon boots and literally me and dad had conversation for five minutes... he had the biggest smile on his face because I didn't turn around and say we haven't had a good night".* [field notes: Despite the emotions there was also a sense of pride in her tone about being able to give this experience for the parents and trying to bring in some normality in their stressful life, even if it was for only a moment] (Nurse Agnes)

5.2.2.3 CATERING TO RELIGIOUS AND SPIRITUAL NEEDS

A significant part of providing comprehensive support to parents undergoing bereavement was related to their religious and spiritual needs. It was noted by all participants that efforts were made to ensure parents' religious needs were met. In their view, even during the emotional upheaval of end-of-life care and decisions, spirituality brought hope and peace to parents.

> *"The most recent experience I had the family were Hindu and as it was exceptional circumstances, we allowed the extended family to come in and we also facilitated someone that they had chosen like religious figure for them to come in and sort of lead a service, before the baby passed away and so in that sense we were caring for all the family and trying to give them memories to make with the baby".* (Nurse Savy)

5.2.3 THEME 3- COMMUNICATION AND INTERPERSONAL ENGAGEMENT IN NICU

The third theme is focused on the nature of communication and interpersonal engagement of NICU staff with parents and families in the NICU. Communication is a critical component of healthcare in general. Due to the nature of situation in a NICU, communication needs of parents were perceived to be more complex, that needed sensitivity of handling and

engagement by staff. Often theoretical knowledge was deficient and practical experience was valued as staff tried to maneuver between the demands of their role and the needs of parents.

5.2.3.1 BALANCED AND EMPATHETIC COMMUNICATION

All participants interviewed acknowledged that in a NICU environment, communication needs are intense due to the fragile status of parents and the uncertainty of the situation. Staff observed the challenge of ensuring they maintain balanced communication. By balanced communication they often indicated being truthful and moderating their expression of emotions.

> *"We're just trying to support… Whenever they ask something, you try to be as clear and as truthful as possible, even if it's uncomfortable for them to hear because if they ask you, will he ever be able to eat on his own? And the doctor has said, probably not… you try to be as truthful as possible, but at the end you cannot…you don't want to make them feel guilty for anything".* (Nurse Anne)

One of the doctors explained how she tried to maintain balanced communication with parents, by being realistic but also not being too devoid of emotions. She believed that being realistic helped her in communicating the right message that enabled parents to see a clearer picture. At the same time, she felt as a doctor it is important that they don't snatch away any hope that parents might be holding on to. She tried to make sure she facilitates bonding between parents and their baby, irrespective of the limited time they may have.

> *"One of these things that I try not to be is very, very melancholy around the patients, and also try not to be very void of showing any emotions as well at the same time. So I try not to be very sad or to approach your parents in a very sad way or in a way that would make them feel even more hopeless than the situation is allowing for, because what that tends to do is that it tends to make the parents… it really, literally removes any glimmer of joy that they might have.. any glimmer of hope.. them they themselves*

might be holding onto. I mean, yes, you want to be realistic in in the baby's prognosis, but at the same time you don't want the parents to feel as though you don't want them to become so disheartened that they just give up altogether and just not want to fight anymore". (Doctor Diana)

Staff acknowledged that parents always had questions. Often some of those questions were directed at the nurses, who found themselves in a dilemma, whether to speak the truth or protect parent's hope. This dilemma caused them distress and there was no guidance available for them on how to address such a situation, other than learning with experience as they grew in their role.

"..they usually speak with the doctors first and they come to you knowing what's going on and it's from do they seek more like…I don't know questions that maybe they haven't asked the doctor or your opinion on how the baby will do or your experience or one other babies. And so it it's hard you know to answer truthfully, because.. you can see babies that do well, but you know… you cannot tell them that.. it might not be the situation and you don't want to give him false hope. At least me, and so it's you know, sticking to what the prognosis is sometimes can be hard…" (Nurse Anne)

Staff described how in the NICU, parents are in a vulnerable state of mind and are likely to hold every single word that is said to them. To avoid causing any hurt, nurses directed some of the questions asked by parents to the doctors.

"As a nurse as well, often all the questions get directed at you, but some questions I feel I can answer, but often I think I'll direct them to the medical team because… These kind of circumstances parents will hold on to everything you say, and that's quite a big pressure because you think if I say the wrong thing or something that could be misconstrued that will be remembered forever for them. And so it was really about kind of being open but also…not kind of… not giving too much away and kind of directing those sort of questions to the doctors to answer because that's kind of their role, and

we're here to kind of care, care for the baby, provide the nursing care and support for families". (Nurse Savy)

Even in babies where death may be expected and staff had repeatedly discussed the possible outcome, some parents got excited with little wins and found hope for their baby. Staff said that this is where ensuring balanced communication was a complex task. They found themselves in a dilemma, trying to maintain neutrality of tone, while being empathetic towards parents.

"It didn't look like the baby would survive for very long. We put a catheter, and the baby wasn't passing urine, essentially because the kidneys were not working at all. And so sometimes we flush the catheter to make sure that it's not blocked, so the saline that we flush in will come up again, and then the parents will see a few drops of the saline coming back out and then they will think oh actually that's urine and then they get very excited. Or could this be the kidneys working again? And then you are in a position where you have to really watch what you say so that you don't end up giving any kind of message that gives them even more hope. So it has to be a very guarded conversation with those kind of parents". (Doctor Sofia)

Most nurses believed that parents want to feel that their grief is shared by the staff. They feel supported and comforted if they know the nurse or doctor who has spent time caring for their baby is also affected by his/her death.

*"You kind of...you have this professional front, but we are all humans so… If it didn't affect me in some way, I'd find it strange. I think... you don't want to get too hardened and because parents want to see that you're upset, they don't want you just to stand there and almost like it's just another day.. because it isn't, it's neonatal death is still, it's not common, luckily…" (*Nurse Savy)

5.2.3.2 CHALLENGES OF BREAKING THE BAD NEWS

Communicating with parents involved breaking the bad news at some point. Depending on the nature of death, i.e. *expected* or *unexpected*, the intensity of communication varied. In *expected* cases, where the baby had been gradually deteriorating and parents had witnessed the decline, breaking bad news concerned discussing palliative care options or withdrawal of active and aggressive treatment. Even though the parents did not always agree, they saw it coming. However, in scenarios where the baby had experienced a sudden deterioration, it was a complex experience. Although such conversations were led by the medical team, it was the nurses who were first to face parents. They described it as an intense experience where they prepared themselves emotionally as well as professionally to withstand the questions parents had while continuing to support them.

> *"So if you are going to… breaking of bad news today there is a plan that the consultants will say okay at two o'clock today we're going to sit down with the parents and then we need to discuss about the direction of care and as the baby that is very sick and dying and prepare the parents that this is the plan of care so with that.. so you so if that is your allocation for the day, so you are going to prepare yourself, prepare your patient and prepare the rooms… so when they come either you say how are you and then you know you update the parents about what happened overnight that the baby had deteriorated because the first thing they will speak is the nurse when they come in because the doctors are doing something, so you kind of alert or tell them that the baby has deteriorated last night…"* (Nurse Lauren)

The medical team made preparations before they were due to have such conversations with parents. They understood the complexities involved and tried to understand the background and context of parents and other factors involved. It was perceived that staff with more years of work experience gained better understanding over time from working with parents and families. For some, having a personal experience was an unfortunate advantage as it allowed them to be more empathetic towards parent's needs of communication.

"It's never a comfortable conversation, like … I would sometimes .. I would think in my head before like what I want to say. I have to get the right words… and then it's also gathering information from people who spoken to the parents to know what's sort of parent are they, like, you know, are they? Are they? What's their background they have they tried for child for very long, and then they have a pregnancy. And then it's this unfortunate outcome. Or do they have other children at home? Uhm, you know what's the family set up so it is never an easy conversation, but I am now a bit more confident about doing it..." (Doctor Sofia)

"Yes, definitely because it [personal experience] *helped me to... Because it helps me to understand where parents are coming from….I learned at that point in time, how as a family member how to deliver bad news like because that's not different news… That's bad news.. to deliver a proper bad news in a proper way". (*Doctor Diana)

Breaking the bad news to parents was not easy for staff. Due to the nature of the situation, parents were extremely distressed which was also reflected in their conversations in the NICU. Staff shared instances where conversations turned into allegations resulting in them feeling hurt. Nonetheless, they tried their best to empathise with parents and support them through their difficult times.

"It was extreme premature baby and that they… it wasn't in baby's best interest umm you know just to stay on the ventilator and the baby wouldn't be able to survive without it. And the mum, there wasn't a dad in the picture. The Mum was very, very angry and she accused us of…being a business and that we basically wanted to kill her baby so we could get other babies in… And that was really hard to hear because it was…. a very intense conversation. I was there as a sort of… almost like…. I think it made me feel sad because it made me feel like… At the time I thought. Oh God, so are we not.. are we not doing a good job at this? Am I not?... my job's never been described as just being something of a business like it just felt everything that the NHS wasn't and… but

I think it was also just a... I felt okay every parent is so different... accept and also validate their feelings". (Nurse Savy)

One of the participants explained the challenge of getting through to parents while having the difficult conversations. Sometimes parents withdraw from the dialogue as a response to their emotional upheaval. In that moment it becomes difficult to bridge the gap between themselves and parents and establish open channels of communication.

"I find a lot with this consultation is once you get to that point you don't know how much more they're absorbing. If you go into very detailed. Which is why I don't tend to… because I don't think you know by that time, I think there's already a wall and in their head they're already thinking and not really absorbing what you're saying". (Doctor Sofia)

5.2.3.3 CONTINUITY OF CARER AND COMMUNICATION

Some of the staff talked about the importance of maintaining consistency while communicating with parents in the NICU. In a fragile state of mind, any form of discrepancies in communication can have a traumatic impact on parents. One of the senior nurses interviewed shared an experience where she advocated for parents when this was not ensured.

"I had a 25 week baby who was really poorly.. Mum was really poorly…she'd had to be moved to the surgical high dependency unit.. The father of the baby and granddad were on the unit, so the consultant went and spoke to the parents and said, you know, your baby is incredibly sick but just yesterday I had a 24 and 25 weeker that went home…painted a lot of hope… So then that consultant went home for the day and we had another consultant…for the night shift…this was now a male consultant and he came up to me and on ward rounds…said to me this baby is not for chest compressions... It's not for any medications, so if the babies to deteriorate we will change the breathing tube only. And I turned around said to this consultant and I said,

you cannot make that decision without speaking to the parents [field notes: there is assertion in participant's tone]*… I said..the previous consultant had just painted the picture that this baby is going home..so we cannot change the… how as medical team can we make the decision that actually we're not going to do anything if this baby deteriorates?...so we then had to go down to the surgical high dependency unit to see the family to basically tell them that their baby was really sick. And he wasn't sure if their baby was going to make the night. Now that was a completely different conversation to..... However, it was the right conversation we should have had two hours earlier. That baby died within 24 hours".* (Nurse Agnes) [Bold = participant emphasis]

While noting some of the challenges and complexities of communication in NICU, one of the doctors' interviewed described how each clinician has a different style of communication which potentially affects parents' interpretation of the message. She described how the interpretation of the message could be different from what was originally intended but may have a snowball effect on further communication and relationships established between the NICU staff and parents.

"Yeah, so because the nature of the job is we work shift base right? So, in a week they'll meet so many people from different consultants, certainly different registrars in different SHOs. And one of the things that they would not intentionally, but they would ask everyone who's come to see the baby and say you know, how's this baby doing? So, they'll ask the day team and then they'll ask the night team again and even saying things like oh, you know I think he's doing alright or he's doing the same. Uh, they can interpret it really differently, so I feel like in such babies where you know, you know that clinically, you're just buying the parents some time that there's no way that this baby is going to survive, then even saying things like he's stable or he's OK is something that they can take very differently from what you intended to me". (Doctor Sofia)

Continuity of the carer (staff) was key to ensuring consistency of communication as well as in maintaining the relationship with parents. Whilst it may not be possible to always manoeuvre the structural issues of staff rotation and shift changes, staff reported that around the time of baby's death parents can benefit emotionally from having a staff member with whom they have established rapport. Ensuring continuity in such times was described being important for staff as they worked towards creating an optimal experience for parents.

> *"I felt it was quite privileged to be able to look after the baby then, and I was actually allocated to different patient, but I asked to be to look after this baby because I built that rapport with the parents and I felt it was important to have that continuation and they had that trust with me and I felt that rapport and also as a professional as well almost to kind of… let the baby go as well, yeah…" (*Nurse Savy)

5.2.4 THEME 4- AN EMOTIONALLY INTENSE EXPERIENCE

In the final theme of this chapter, we look at the impact of newborn death on staff and their personal engagement with that experience. Staff talked about co-existence of multiple emotions and their efforts to navigate them as they strive to continue working with and supporting parents.

5.2.4.1 EXPERIENCING GRIEF AND GUILT

Death of a newborn was described as a difficult time for NICU staff. They shared their experiences of developing a bond with the babies as well as their parents, and experiencing immense grief, especially if the baby had spent a long time in the NICU. There were instances when parents refused to be with the baby at the time of their death and it was nurses who held and cared for the baby in its last moments, an experience that was emotionally intense and challenging.

*“When the baby that I was looking after died so unexpectedly. And I was the only one…I was alone preparing the baby. That was really down.. that was really hard for me…preparing, dressing the baby, getting the tubes out and getting the hair and you know…” (*Nurse Anne)

“It has not affected me professionally….emotionally I struggled to pass ITU [Intensive therapy unit/NICU] *I'm really glad that I am not in ITU this week to pass and see that cot space empty. I am really glad, and I've heard other nurses say it's hard to… It's hard to pass and see his cot space empty. Or to see another mother-baby in it you know. So, I think people are going through the emotions, all of us”.* (Doctor Diana)

Nurses spent considerably more time with the parents compared to doctors, supporting them through the NICU period, through their anticipatory grief, uncertainty followed by death and bereavement. Their involvement was much more personal in comparison to that of doctors who were more *task orientated*. Even though their role expected it, not all nurses were able to support and get involved with parents during this period and found it emotionally difficult.

“I think when you've done the end-of-life care, so once you've end, once you've stopped treatment… We then bathe the baby..do handprints and footprints. We take photos. You know that's when it's just the nurses, doctors don't do any of this.. Once the doctor have had that conversation that perhaps we're stopping everything. It's then the nurses that do it all. The only thing the doctor at, the only thing that sounds awful what the doctor has to do is to come and listen into the baby to see if it's it's passed or like when the baby has died. By that time you've been in a room with a parent in their most worst grief. Trying to make… joining your head to make sense of everything but trying to support the parents at the same time, trying to give them memories with the bath, the photos, dressing the baby... You know that’s hard and not all nurses can do that. And you can't teach how to do that”. (Nurse Agnes)

Nurses often developed a sense of a belongingness with the baby. They described it as the nature of their job and engagement with the family that facilitates closeness. They were close participants in family's day-to-day life; getting to know their fears, uncertainties, and anxieties. There were experiences where it no longer remained a patient-nurse relationship. They developed a bond that was deeper and hence, the hurt and grief with the baby's death was experienced more personally.

> *"They ask us what are the other options? So, I said we can easily facilitate in one room. We do have a separate room over there. It's called* [names the room]*, which is empty, so it's going to have a room over there. We can arrange a comfy chair like a recliner chair so you can rest. You can stay with the baby as long as you want. And then when you are ready, we can facilitate that so that she don't need to suffer any longer than that. And then that's it. I think it will be better place for her too, to die here because she has been taken care of, we took care of her very well and she belongs to* [names the NICU] *and this is a better place for her"* [field notes: participant starts crying and does not stop. We took a break from the interview for a few minutes, as she needed time to feel okay. It appeared that she felt emotionally connected to the baby. She felt she needed closure from this experience but would not have it if the baby was taken elsewhere to die]. (Nurse Naomi)

In addition to the sense of belongingness, nurses also had a sense of responsibility for the baby, after caring for him/her throughout their limited life span. It was perceived as a personal responsibility for them to ensure a peaceful send off to the baby and to make sure the baby was loved and cared for. There were instances where parents did not want to be present during baby's end-of-life care and at the time of death and in such times despite the emotional trauma, nurses made sure the baby was looked after with the utmost love and affection.

> *"He was a 34 weeker* [weeks old]*,..We tried to have talks about redirection of care to the point where parents refused to speak to the medical team. They came in three*

times a week, stayed for less than half an hour and that was all they visited. In their head they wanted him to get to a term baby because they thought when he got to term everything would be OK. It wasn't. We ended up withdrawing on this baby, aware, but, but only when they said so. So, we kept this baby alive for eight weeks. It was incredibly hard. This was the hardest thing a, as the nursing team we've ever done because we were the ones caring for that baby. We would change his nappy, or we would read him stories. I made sure that when I was on shift, I had half an hour cuddle time…And that was just their [parent's] *coping mechanism, wasn't it? They had a date in mind. So eventually when it did come to withdrawing a treatment… they turned said we are ready to do it today… the nursing team lead it...mum and dad had cuddles. Then mum and Dad went home… And then it was up to us as nurses to sit with him until he took his last breath and that's what we did. We took it in turns. I did an hour. My friend did an hour… I stayed till 11:00 o'clock at night. Because for me I wasn't going to leave until I knew the end... And so, I think as nurses and doctors are very differently made up, doctors are very medicalized nurses are very…more I don't know more person, I don't know more personal…"* (Nurse Agnes)

Similarity in personal situations and relatability added to the intensity and complexity of experiences. Staff talked about the emotional turmoil that they undergo when working with a dying baby. They felt sadness, anger, and grieved in a manner that was unique to themselves.

"Obviously, we have sadness and sometimes anger of why this is happening to these babies and... You know, I, I think it's the personal process that you go through with every death because you think you will get used to it but you don't... For me now, it's harder actually after I have a baby, I thought it wouldn't make a difference at the beginning, but it does..So you kind of imagine what the parents are feeling, but you cannot imagine their feelings right?" (Nurse Anne)

"I knew professionally that it had to be done, but..to see it as a woman and as a future mom just to see that happen.. have to happen and I have to deliver that news… It was I felt it in my heart. Like literally. I felt it. I think this is the one I felt the most… I've ever felt". (Doctor Diana)

Nurses talked about the *unexpected* deaths and how these were daunting experiences for them, especially considering that parents had no time to mentally prepare themselves. Sometimes in such cases parents could not be present by their baby's side and the baby died alone. Nurses found themselves in shock and in denial. They also felt guilty and experienced self-blame as they wondered if it was them who caused the baby to die.

"[In] *sudden death… you question yourself,* [if] *I've done everything…I feel like guilty I should have not left or blame someone like why you do some procedure without me and then… Because you know that baby is your responsibility…you're like assessing what happened… which is really bad.. you feel bad because as I said you know the mom will come…you will call them up, mummy, could you please come…I want to let you know that the baby..your baby had deteriorated and suddenly and is now on the ventilator…and when they come you know they look at you in front of your face asking what happened*…" (Nurse Lauren)

"So I started my shift, the baby was stable, was doing fine and then that baby… he started to get very sick, very unwell and within six hours the baby was dead. That was really that was one of the worst times that I…[field notes: participant pauses] *You keep wondering what you haven't done? What you could have done? What you did wrong? What are you going tell the parents? How are the parents going to react?... because those parents didn't have time to say goodbye to the baby, it was the middle of the night. We were trying to do everything for the baby and at the end of baby passed away… which was a very horrible way to die"*. [field notes: participant crying while narrating this experience] (Nurse Anne)

5.2.4.2 PREVAILING EMOTIONAL DISTRESS

With *expected* and gradual deterioration where parents wished to continue with active treatment, staff experienced distress. They reflected on the quality of life of the newborn upon survival and its eventual impact on the family. Sometimes they felt that it was *selfish* of parents to keep the baby alive, overlooking the pain that the baby was feeling. At the same time, they are trained to respect parent's wishes and sympathise with them.

> *"I think you know the deaths are very hard. But the I think it's much harder to have a baby with disabilities or knowing that the baby is not, never going to walk or never going to talk or not going to, you know, have a normal life. I think that's much harder than….. That makes me feel… sad or angry…because that baby is not going to have a life. So, so I guess you just want to keep it…I mean he might die in a couple of years so. I don't see the point they keeping that baby alive, making him suffer, keeping a tube down his throat* [her tone reflected frustration] *just because you want to keep him alive. It's selfish. The baby is in pain…"* (Nurse Anne)

Doctors who were in-charge of leading treatments reflected on the impact of their actions and treatments on the baby. One of the doctors interviewed talked about experiencing moral dilemma when she is working with extremely premature babies. She described finding herself pondering over the long-term impact of the NICU experiences on the baby if it survives and felt responsible for causing pain to the baby. She found herself torn between supporting parents and advocating for the baby.

> *"You have to go to those deliveries, and you have to tell these parents these are the statistics, and of course for them even if you give one percent or two percent, they want to take it, especially if a mother has lost so many miscarriages, they want to try... It's very tricky.. and sometimes they do survive, and I feel… if they survive and if they are in intensive care, you are doing this whole lot of procedures on them and we don't know what their pain threshold is, what they are... what the babies are going through,*

and what they will have when they grow up, what kind of experiences they may have.. We've had in Paediatrics, we've had certain preterm babies who have grown up and who come to us and they're literally scared of needles, and they have really low pain threshold, and it's all because of the NICU experience and we don't know enough of what these babies experience. So yeah, I think that's bit of a problem". (Doctor Kristy)

5.2.4.3 SEEKING STRATEGIES TO COPE

Due to the highly intense and emotional nature of engagement in the NICU with parents, each staff member developed their coping mechanism which were necessary for them to continue working with and supporting parents. It often came with years of experience, but all staff shared different strategies they used to cope with their experiences of newborn death.

For many of the staff interviewed, seeing other babies recover and go home from the NICU was a very positive motivation. It gave them hope, positivity and the strength to carry on with their job.

"I think it's difficult to come back the next day, but then you also see the babies that get better and that go home absolutely fine after a very long journey in the NICU. That's very satisfying." (Nurse Anne)

"It reinforces how like to the fragility of life. And you know, sometimes they're intertwined…. There's always light amongst darkness…. I'm really glad to hear lots of screaming babies, whereas some days it does drive you a bit crazy and umm and you know, I thought God like be thankful for screaming babies… " (Nurse Savy)

For a few staff, spirituality was helpful as they coped with the stress of a baby's death. It allowed them to look beyond the occurrence of death and accept it as a natural phenomenon. For some having a relationship with God was helpful because they felt that despite the negative outcome, their efforts were seen and acknowledged.

"I think for me.. because for me death is like a natural thing happened. My perception of death is natural.. we are here and someday we will die…" (Nurse Lauren)

"... And even if things don't come out the way that you wanted it, like God understands that you have tried as best as you can within or like your capacity and resources". (Doctor Sofia)

Another nurse noted how believing and talking to the baby as a living being after its death, helped her perform her duties. It was a mechanism she had developed over the years of service and experiences of working in the NICU.

"Now this is going to sound really weird…when I'm dealing with babies that are unfortunately passed.. the way I cope with it is in my head I have to pretend they're still alive when I'm doing things. So for example, we was giving him a bath so I use his name and I'll be like, oh, like baby, I'm just going to wash you and I literally talk all that…… So I think that's probably where my coping mechanism comes in more by referring to the baby as their name, by referring to mummy and daddy, because it helps me be able to nurse". (Nurse Agnes)

For some, a gesture of kindness was enough to cope with an emotionally tense day. It brought them a sense of support and acknowledgement from their colleagues, as well as reassurance that they were not going through it alone.

"Another thing which helps to cope probably is, I don't know it's there… If it is very stressful day like you know someone… a genuine person come and say give you a hug like it's OK, we can go through together. You know something like that. It's more than enough" [field notes: participant is emotional but shares a smile]…(Nurse Naomi)

Most staff were not keen to use the counselling services offered to them by the NHS. They felt it was not very helpful in understanding their needs in dealing with the emotional impact of newborn death.

"Yes, they do this kind of after the death they do kind of meetings so that they can get support from the psychologist... Do I go for those meetings? it's very rarely I go. I think at the beginning when I was very new to neonatology I used to go. I never felt it's kind of supporting. Just asking the same thing you're going through…talking about the same thing over and over again..... I don't know about others, I maybe I'm kind of introverted person. I'm not very outspoken. I just pray to God and that's keeping me.. keep going". (Nurse Naomi)

For most participants, having a supportive team and colleagues was the most effective means of coping in the NICU. Junior staff looked for guidance from their seniors to discuss their experience and challenges faced. It was reassuring for them to know that they have the support from the senior staff as they learnt to navigate the challenges of bereavement and newborn death.

"I mean, when you have when you have a person there guiding you or supporting you, even whatever experience you have because you can be very experienced and then maybe because…your personal situation I think also influences your mood and how you are on the shift… you are human… you cannot put that aside and sometimes these things hits you harder than others. And I think the person, the team around you, not only the nurse in charge, the team around, your colleagues and everything that makes a lot of difference on how you process and how you handle situation". (Nurse Anne)

On the other hand, senior staff understood the complexities that came with the job. They acknowledged the support that junior staff needed in bereavement cases, especially since steering the emotional aspect of working with dying babies and their parents required on-the-job training.

"A lot of the junior staff... I think in the last in a month we've lost four babies and I was on shift for three of them. And I didn't leave the [junior] *staff's side. I didn't leave the nurse that was looking after that baby at all, but everything else could wait because*

she needed me to just get her through it. And I'm like after a shift like that I will have text messages coming through saying thank you for what you did. Because it gave them a nice experience so that when they've got to do it next time, and perhaps I'm not around and they might not have the support they want, they know they can do it". (Nurse Agnes)

Nurses discussed the way a collaborative relationship with the doctors made the dynamic more comfortable for them to work together towards the goal of giving parents a positive experience. In terms of support, most nurses noted their expectations from doctors to share more responsibility in spending time and supporting parents, and thereby taking some emotional burden off the nurses' shoulders.

"The doctors potentially getting more involved because…I think by parents they sort of break the bad news and…that's kind of almost. That that's what the association is…so I feel from that sense… it would be good to have more support sometimes for nurses because we are just…you know they come in and out and we are there and… but it's quite a lot and our role entails so much. And obviously a doctor's role is very busy too.. But I think it is very nurse lead which actually for such a big thing is…it's quite a lot. So.. I think maybe more doctor involvement…" (Nurse Savy)

5.3 "*AT LEAST YOU HAVE DONE SOMETHING FOR THAT FAMILY*" – THE PHENOMENON OF CREATING AN OPTIMAL EXPERIENCE FOR PARENTS.

Although NICU is a specialised facility to look after sick newborns, NICU staff felt equally responsible for supporting parents. Throughout their narrative of caring for babies and working with parents whose babies died in the NICU, there was an underlying phenomenon of creating an optimal experience for parents amidst the adversity. While the endeavour was towards parents, it was also a coping mechanism for staff that helped them carry-on with their own responsibilities. Whether it was facilitating time and space for parent-baby closeness,

understanding parental needs, providing tailored and individualised support, or ensuring empathetic communication, all their efforts towards supporting parents helped them find meaning in their job. Despite the sadness and moments of distress accompanying the death of the newborn, they had a sense of accomplishment and a feeling of contentment, when they gave positive memories for parents to take back home. It acted as a motivator, helping them to retain confidence in their job and the strength to keep going. Positivity protected them from enduring emotional anguish. Feeling that they did everything that was possible for that baby as well as for parents, and that the baby died being loved and cared for, was comforting for them. In contrast, in its absence they were fragile; prone to self-doubt, blame and a loss of control over their environment. Striving for an optimal experience for parents by doing everything they could, was also a coping mechanism they were not necessarily explicit about but focussed their efforts on.

5.4 CONCLUSION

This chapter examined NICU staff's lived experiences of newborn death and supporting bereaved parents in the process. Analysis of revealed an overall phenomenon, 'Creating an optimal experience for parents. Four themes helped build further understanding of this: 1) Facilitating parent- baby closeness; 2) Providing comprehensive support to the family; 3) Communication and inter-personal engagement in the NICU; and 4) An emotional experience. The findings have uncovered the difficult journey that staff experienced with newborn death but felt unprepared for. Experience brought in the understanding that having a mutually trusting relationship between parents and staff is of critical importance to ensure a collaborative decision-making process and experience. Key elements of this process were highlighted. Staff described how they worked towards building a relationship with parents and attending to parental needs, sometimes reportedly going above and beyond their expected roles. For nurses in the study, emotional involvement was almost inevitable, especially due to the nature of their engagement. The experience was often emotionally challenging, and

although seniority brought an understanding of dealing with newborn death, it did not make it easier. Finally, the phenomenon of creating an optimal experience for parents as a coping mechanism was described to deepen the understanding of staff's lived experiences and how it is a mechanism that remained implicit throughout their engagement with newborn death and bereaved parents.

CHAPTER 6- DISCUSSION OF STUDY FINDINGS

6.0 INTRODUCTION

This chapter will discuss the findings of this thesis derived from the complementary studies on lived experiences of parents and staff concerning newborn death. I will discuss the methodological and theoretical influences, as well as the emergent phenomenon that will contribute to a comprehensive understanding of newborn death from the lived experiences of parents and NICU staff. I have explored and drawn parallels of parent's narratives with Kübler-Ross's (1969 & 2005) model for grief and personal loss (36, 176) and the Dual-Process Model(40), as the major themes advance these theories and enhance our understanding. The chapter will conclude with a discussion on the strength and limitations of this study.

6.1 DISCUSSION OF FINDINGS

This section will discuss the major findings and themes relevant to developing a comprehensive understanding of lived experiences of newborn death. The discussion will draw on published literature and discuss the essence and meaning of lived experiences of parents and staff who participated in the study.

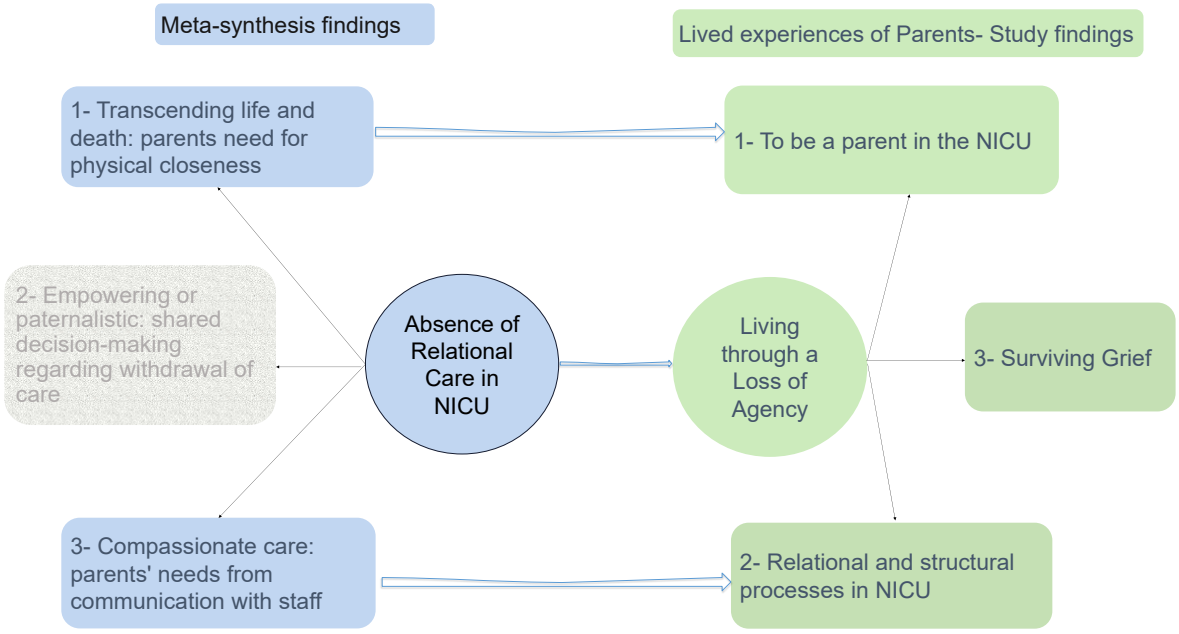
6.1.1 EXAMINING LIVED EXPERIENCES OF PARENTS

This study explored the lived experiences of parents whose newborn baby died in a NICU in the UK. The methodology was Hermeneutic Phenomenology, influenced by the interpretative school of Martin Heidegger (1962) with analysis further guided by Van Manen (1990). I

attempted to gain in-depth understanding of this experience from the parents' perspective. It would be important to note that despite the volume of literature available about specific NICU experiences, the topic of parental and staff experiences of newborn death remains to be less well discussed. To the best of my knowledge there are no studies conducted in the UK where parents were asked about their overall lived experience of their newborn's death. Despite the extensive nature of this study, I do not claim to give definitive answers about this experience. However, as pointed out by Gadamer(134), the study tries to gain an understanding from the narrative of bereaved parents and from their unique "horizon" which was time situated(134). I remained a key and central element to the analysis as I interpreted parent's narratives. Hermeneutic phenomenological style of interviewing allowed me to approach participants in a manner that was open, relatively un-structured, not strictly engaging with pre-determined concepts or theories; thereby allowing participants to weave their own story and control their own narrative.

Before discussing the study's findings, it is also important to point out that while data from parent's lived experiences broadly agreed with the findings of the metasynthesis, this study advances the understanding by deepening the engagement with narratives of bereaved parents. The metasynthesis reviewed and analysed 20 original research papers published and revealed three core themes, 1) transcending life and death: parents' need for physical closeness, 2) empowering or paternalistic: shared decision-making regarding withdrawal of care and, 3) compassionate care: parents' needs from communication with staff (see chapter 2). While the hermeneutic phenomenology study of parental lived experiences was an independent enquiry, the meta-synthesis contributed towards building an understanding of the published evidence on parent's experiences of newborn death. Due to different and specific study focusses (as discussed in section 2.3.1- Limitations), none of the studies explored overall parental narratives in-depth. Two themes of the metasynthesis (1 and 3) occupied some part of the two themes (1 and 2 respectively) of the parental lived experiences study. The diagram below illustrates the relationship of themes between the two studies.

Figure 6- Relationship between metasynthesis and study of parental lived experiences.



The emergent phenomenon from the study of parent's lived experiences of newborn death was that of loss of agency experienced by parents in the NICU. Agency is a sense of control over one's life, actions, and decisions. In our day-to-day lives, we undertake voluntary actions, and generally, we do not feel as though these actions have simply happened to us. Instead, there is a feeling that we are to some extent in charge and in control(177). The sense of agency is this feeling that one has of being the driver of one's own actions.

To be a parent in the NICU- Parents entered the world of NICU afraid and uncertain of the future. Baby's admission in the NICU was characterised by a difficult parent-child separation. Parent's need for physical closeness with the baby and the impact of NICU environment on parent-baby bond was reported in the meta-synthesis (see section 2.2.3.1- Theme 1). A unique acknowledgement of the metasynthesis was that of the transcendental needs of parents to maintain closeness with the baby from birth to death and the impact of being present

around the time of death in parent's sense of self and long-term grief. A literature review examining parental outcomes after stillbirth concluded that parents who saw and held their babies had a better adaptation and acceptance of their bereavement(93). The results from the present study on newborn death are similar, and the two mothers who reported not spending time with their deceased baby experienced symptoms of complicated grief and continued to live their lives in regret. Along the parental journey, the NICU environment was characterised by stressors including sick newborns, medical equipment, and busy staff, where parents did not assume the expected role of being the baby's primary carer.

Alienation was reported. Parents reported feeling *isolated* and *exposed.* Although there was no explicit mention of distrust towards the medical team, parents constantly felt like outsiders despite the NICU being an integral part of their lives. It is not unexpected that parents reported feeling overwhelmed and alienated. Previous studies have shown how mothers in the NICU felt excluded from baby's care and unwelcomed (178, 179). A meta-synthesis on mothers' experiences who had a preterm infant in a NICU highlighted the challenges they faced in finding a sense of identity as a 'normal' mother in a NICU environment which encompassed similar emotions to the theme of 'To be a parent' in my study(180). A study conducted on assessing the factors that parents found helpful in coping with the NICU found that the physical environment of the NICU played a critical role in parental ease and satisfaction(181). Most parents in this study had no prior-understanding or experience of a NICU and did not know what they could expect from that environment, which added to their feeling of alienation. A study looking into maternal mental health and NICU environment in a level III NICU in the Midwestern United States showed that a thorough explanation of the medical equipment and the purposes behind alarms and alerts (*lights* and *noises*) helped relieve maternal stress in a significant degree(178).

Supporting and empowering parents to have an active role in providing the care that is possible under the circumstances is important. Despite increasing efforts towards family-integrated care in NICUs, families experience still disempowerment. It is so because they have

little to no control over their child's situation(182). However, in this study disempowerment was further characterised by parents feeling silenced and finding themselves voiceless, unable to ask questions or seek answers about their situation. Some of the mothers compared these feelings to the cultural subjugation experienced by women in different parts of the world, an analogy drawn uniquely in this study. Although, this aspect has not been explored in neonatal bereavement, there are studies in stillbirth that have explored the cultural silencing experienced by women in healthcare settings. In Sub-Saharan Africa, due to various social norms, women are often denied the opportunity to share their experiences or mourn openly within communities as well as healthcare settings(183-185). These restrictions imposed on women reduce their capacity to seek help and further increase the risk of psychological complications and complicated grief (186). Furthermore, this finding can also be understood in the context of the paternalism experienced by parents in the NICU, a finding from the metasynthesis (see Section 2.2.3.2- Theme 2). This theme was specifically related to decision-making in NICU, but parallels can be drawn between the shrinking autonomy experienced by parents and subjugation experienced by women, leading them to withdraw from the NICU environment and curtailing themselves from asking questions, sharing doubts and worries. The recently published MBRRACE-UK reports on women's experiences of stillbirth and neonatal death mentioned the disparities in care received by Black and Asian mothers in comparison to their white counterparts(11, 12). Nonetheless, this remains an under explored area that requires urgent attention and critical exploration as women may be experiencing double marginalisation in the NICU, as a parent and as a woman, and therefore stand at the heightened risk of being vulnerable to complicated grief.

Relational and structural processes in NICU- Communication was a key theme throughout the literature on parental experiences of NICU. The metasynthesis revealed an emerging theme that recognised compassionate care and communication with NICU staff as a key tenet of influencing parent's experiences across the included studies (see Section 2.2.3.3- Theme 3). Therefore, it was foreseeable that communication and interpersonal engagement of parents

and staff would be a significant part of parental lived experiences of the empirical investigation. Moreover, as themes were not mutually exclusive, supportive, and empathetic communication was a key factor in determining parental narratives of NICU experiences. Parent's stories about their time and engagement in the NICU included both positive reports of supportive NICU staff and unpleasant engagements causing a breakdown in relationships. More often parents noted lack of quality communication with the NICU staff as a major factor in the emotional stress in the NICU. It ranged from a lack of understanding among staff regarding parent's expectations; excessive, absent, or inconsistent communication; to lack of empathy in tone and engagement. Evidence has shown that inadequate and restricted communication between parents and staff can heighten the isolation that parents experience in NICU, causing them to distance themselves physically and emotionally from their baby (187, 188). Studies have highlighted how good listening skills when displayed by clinicians made the patients feel that they are cared for(189, 190). Similarly, respectful communication has been shown to improve maternal satisfaction levels in the NICU(178). Person et al.(190) reviewed the literature on bedside manner in different clinical settings and performed a concept analysis of behaviours regarded as positive or negative, reported consistently by patients. The review categorised factors such as insensitivity, disrespect, arrogance and impatience as negative behaviours(190). Mothers in this study reported several instances of disrespectful communication from staff, which also included signs of cultural insensitivity displayed by staff. This is an aspect of parent's experiences with communication in the NICU that has not been explored in detail in the context of newborn death and the NHS, but contributed immensely to the feeling of worthlessness among parents who were already in a struggle with their (newly established) identity of being a NICU parent. Multiple studies published in the United States have highlighted the racial discriminations and segregation of care endured by some parents in the NICU(191, 192). The MBRRACE-UK report highlighted that newborn death rates were higher by 43% for Black and Black-British babies(11) and 59% higher for babies of Asian and Asian-British ethnicity(12) when compared with White babies. Despite these results, research

to understand the influences of social and cultural factors on care, support, and parental experiences in the NICUs in the UK has been lacking.

Surviving grief- Finally, I explored parents' journey with grief from losing their newborn baby. Commonly reported emotions were anger, shock, disbelief, and denial. Loss of agency in the NICU contributed to parents experiencing a loss of their old self. Consistent with other studies, findings showed how parental grief evolved over time, but did not diminish despite the length of time since bereavement(193-196). On the contrary, the intensity of grief was affected by parent's experiences with structural and relational factors in the NICU. Positive memories remain with parents, while negative memories, disagreements and unpleasant encounters with staff are shown to worsen their grief(197, 198). For instance, in this study few mothers reported distancing themselves from their baby due to the impact of staff's communication with them. They continued to live with regret for relinquishing control over their thoughts and actions and losing limited opportunities of closeness with their baby. A significant number of parents also explained how their grief symptoms were highly intrusive and *crippling*, but none of the parents were clinically assessed for complicated grief. Few mothers talked about suffering from post-traumatic stress disorder. One mother in the study reported taking anti-depressants. Although this study was not structured to understand and comment on the mental health status of parents, there is evidence to show the detrimental impact of child's death on parents' mental health, with parents experiencing depression, anxiety, dissociation, interpersonal sensitivity, aggression, and post-traumatic stress disorder etc(56, 57, 199). Until a few decades ago, infant deaths including stillbirth and newborn death were regarded as "non-events" or "non-deaths", which impacted the support provided to bereaved parents by health professionals(200). While efforts towards generating awareness on the significance of these losses have resulted in development of support programmes for grieving parents, they are not adequately equipped with the knowledge of parental needs in such times.

Previous studies have reported negative impact of perinatal bereavement on family dynamics and structure. Marital distress, separation or divorce and neglected children are among

commonly reported factors(201) (202). One of the studies reported marital disharmony as a result of incongruent grieving styles of fathers and mothers from perinatal death, where women displayed intense reactions for longer periods of time, in contrast to their spouses(203). Differences in grieving styles have also caused difficulties in coping for parents, that further contributed towards disharmony in relationship(204, 205). However, despite a similar variance in mourning and grief reactions between partners, there was no such evidence found in this study. On the contrary in this study, participants felt their bond strengthened due to their different coping mechanism, with newfound respect for one another. These differences are potentially due to under-representation of separated parents in the study.

Although, I did not set out to compare experiences of mothers and fathers, some differences were difficult to overlook. Lack of adequate emotional support for fathers in the NICU and post-bereavement has been widely discussed(156, 206, 207). Similar experiences were evident in the study. Fathers experienced a “double burden”, from grieving their newborn baby’s death and also feeling the responsibility towards their partners and family(208, 209). They felt the need to remain composed, collected, and strong for their family. This, combined with an absence of bereavement support, may contribute to the self-censorship exhibited by fathers. Evidently, all but one father in the study resisted from having an open conversation. It seemed that they feared a catastrophic emotional consequence of our interview.

Social support system, comprising of friends and family, helped parents cope and were available to an extent for most of the parents. However, similar to other studies it did not seem to affect their feelings of isolation(205). This may be due to their experiences of dismissal of loss and hurtful comments received by parents(210, 211) and cultural expectations to move on as fast as possible and pretending nothing had happened(212). Another coping mechanism commonly shared by parents in the study was a subsequent pregnancy or parenting older children. Evidence from studies in stillbirth and newborn death have shown that mothers often find refuge from grief in other children to cope with their bereavement(213). However, pregnancy after loss is also traumatic, as parents live in constant fear of having the same

outcome as before(214, 215), but often it is the only way to move forward in their life. Concerns have been raised about a new pregnancy especially if the mother is not well-prepared(214). However, having another infant after experiencing newborn death also reduces symptoms of post-traumatic stress in some parents(216).

In terms of bereavement support, a novel finding from this study was the lack of support reported by parents in administrative tasks such as registration of baby's death. In the UK, a birth needs to be registered within 42 days of birth. Often when the baby is admitted into the NICU straight after birth, parents may not have the opportunity to register their birth. In this context when the baby dies in the NICU, parents are then required to do their birth and death registration at the same time. Most hospitals in the UK provide bereavement support, that is free of cost and includes bereavement counselling and follow up appointments. It is provided by a multi-professional team that includes a neonatologist or an obstetrician, or both, and a bereavement midwife or nurse(217). However, with regards to the administrative tasks such as birth and death registration, funeral arrangements etc., parents are often left without any guidance. Nearly all parents in the study reported this juxta-positioning of birth and death registration as an extremely distressing experience along their bereavement journey. They were caught off-guard, lacking any previous knowledge or expectation of requirement of such a task and were not emotionally prepared.

Another aspect in bereavement support for parents was the inadequacy of counselling support available, which acted as a barrier for them in coping with their grief. Parents felt their grief was not understood and that they were not taken seriously. A study conducted in the UK examined the uptake of bereavement support services between two NICUs and found that 50% of parents attended the bereavement clinic only once(217). There was no association found between socio-economic demographics and uptake of bereavement support(217). Mothers in the study also talked about the minimal support available for grieving fathers and how that further hindered their ability to share their emotions and restricted avenues for them to process their grief. For bereaved parents to feel that their loss was not considered equal to

other type of deaths has been noted to be unhelpful(218). It is important that grieving parents are provided with the opportunity to openly share their feelings and talk about their baby, in a compassionate and non-judgemental environment(219-221). In the absence of the much-needed counselling support, mothers often turned to informal avenues such as social media and support groups as it allowed them to express themselves and to feel they are not alone in their grief. Such groups allowed them to talk about their baby, share their experience and break their isolation(222, 223), specifically in early stages of bereavement(224). Evidence has shown that expression of emotions might help parents advance in their journey of mourning(222, 223, 225).

Lack of support from the NICU staff and post-hoc from the bereavement support counsellors/midwives as well as families contributed towards disenfranchisement of parental grief. Research in perinatal grief has generally discovered that the disenfranchisement of parental grief is multi-faceted, complex, and intertwined with socio-cultural values, which is consistent to disenfranchised grief in general(226, 227). A previous study examining bereavement from stillbirth highlighted that lack of empathy in communication, characterised by constant use of medical terminology and jargon led to medical framing and reduction of loss experienced by parents(23). Medical framing of loss meant an exclusive focus on the body and physical interventions, and minimal consideration towards emotional trauma experienced by parents(23). This was evident from parental narratives in the lived experience study as they sought empathy and consideration in their engagement with staff, instead of an exclusive focus on the medical description. Absence of adequate information and perceived disrespectful communication from staff compounded the disempowerment experienced by parents by making them afraid to ask questions. Although, supportive avenues for sharing grief were dominantly absent in parental narratives, most parents had some basic form of supportive social network that acknowledged their loss, even if it was from their spouses and in some cases, voluntary support groups. Moreover, almost all parents in the study experienced some form of grief dismissal. Even when their grief was acknowledged it was

categorised as occupying a lesser significance in a socially constructed hierarchy of bereavement, extending the agency loss lived through in the NICU. This led to parents feeling that they were deprived of their right and denied the opportunity to grieve in the manner they found appropriate. In overall terms, the results from this study indicate that while most parents did not experience a complete disenfranchisement of grief, their grief could not be completely enfranchised.

6.1.1.1 UNDERSTANDING GRIEF FROM NEWBORN DEATH

Parents in this study had different emotional responses to their grief, ranging from disbelief to anger and sadness. The trauma that began from their newborn's birth to NICU admission, prognosis, treatments, deterioration, and death, was compounded by conflicting feelings resulting from the engagement with NICU staff. In this section, parental grief from newborn death is examined, alongside two of the previously visited grief theories/models (see section 1.2.1.1). This is important as it provides important perspectives on how to understand and support parents who live through newborn death.

Parent's narratives of lived experience of their newborn baby's death and evolution of grief, resonate with Kübler-Ross's model of grief (35). Denial meant that the parent refused to accept the news to be true. For most parents in the study, their newborn baby's condition, and admission to the NICU was unexpected, which made it difficult for them to accept their prognosis and the new reality. Anger was usually expressed with irritable reactions as parents asked, "*Why me*?". With their intuitive thinking they then moved to the bargaining stage. Those who were spiritual, bargained with God and mostly all bargained with their medical team to continue treatments and try something new. This was in the *hope* that they may be able to mitigate the loss and change the inevitable. Signs of depression appeared as they came closer to the understanding that loss may be inescapable. It manifested in the form of crying, sadness, and yearning for their baby. Finally, parents appeared to reach the stage of acceptance where they gained a definite realisation of the outcome of their newborn baby's

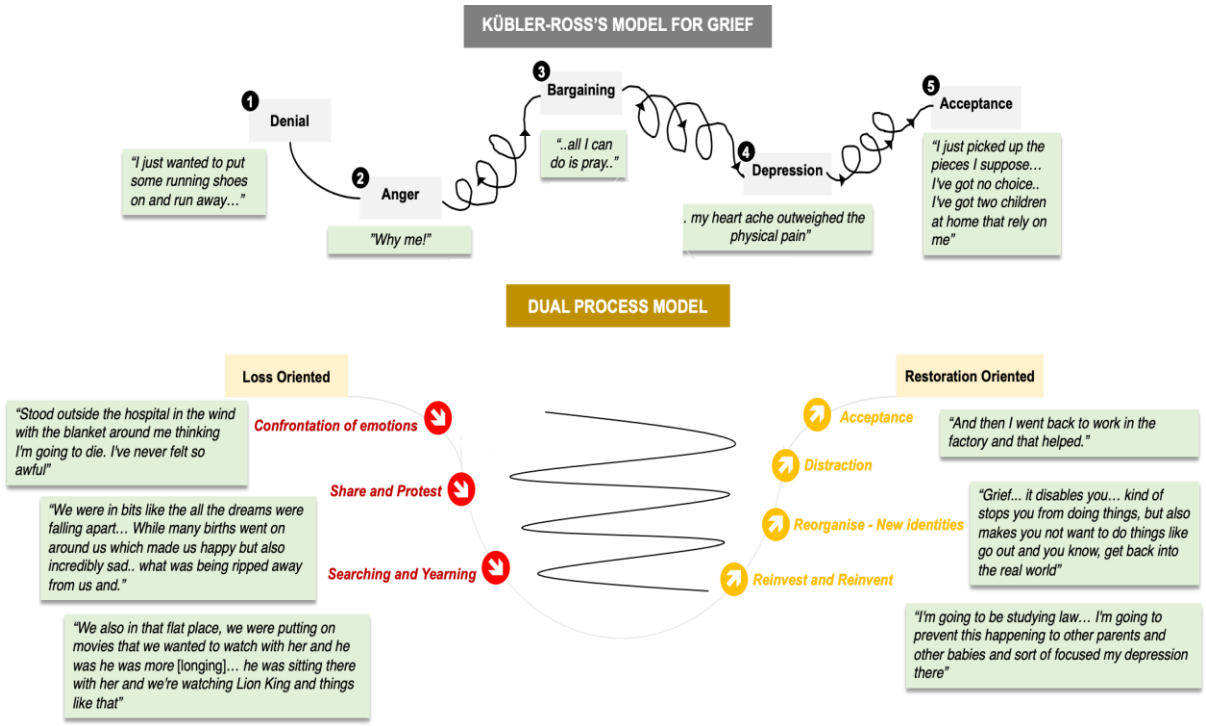
death and its irreversible nature. This stage was also marked by their readjustment to existing relationships and involvement with prior interests or distractions. This was particularly evident in cases where parents had other children at home, who needed their parents despite bereavement. Kübler-Ross noted that these stages are not necessarily linear, and some people may not experience all of them, however most bereaved people are expected to experience at least two(37). As discussed above in the context of this study, I propose that collectively most parents demonstrated experiencing most of these stages in a similar manner, the outlier being acceptance. The trajectory to acceptance fluctuated with circumstances. Parents often oscillated between the stages of depression and acceptance, as the journey was gradual. Despite the time since their bereavement, parents had not found peace in the truth that their newborn baby had died.

Parents' grief evolution can also be understood in the context of the two styles of coping described by the Dual-Process Model (DPM)(22, 227), where both mothers and fathers oscillate between loss-oriented and restoration-oriented strategies. As part of loss-oriented strategies, parents in the study did grief work as they processed their bereavement and experienced and confronted emotions. Although mothers were more vocal about their grief and sought opportunities to share with others, fathers too needed to yearn for and reminisce about their deceased child. As part of the restoration-oriented strategies of adapting to life, both groups of parents, shared the need for taking time off from their pain to deal with everyday life, which included going back to their jobs or immersing themselves in looking after their other children. The healing process involved reconnecting with their family and community as they engaged in rebuilding their relationships and engaging in new relationships, often attempting to move on with a new pregnancy. For some, restoration involved their searching for solace in religion, where they found conviction that their baby's death was part of a *divine plan*. They found themselves believing in an *afterlife reunion* with their baby and found peace in the possibility of togetherness. For a few parents it was important that their grief involved more than mourning their loss. Navigating grief with a purpose was essential as they engaged in

the reconstructing and reinventing their lives. It included their newfound calling in philanthropy or in the desire to help others' who are suffering, ultimately to honour their child's memory and carry forward their legacy. Research has shown that parents who engaged in specific sense making themes may experience relatively fewer maladaptive grief symptoms(58).

The diagram below (Figure 7) presents an illustration of the two models along with some parental quotations to aid our understanding of how parent's grief evolved. The process was not a linear one and parents oscillated between different stages as explained by the Kübler-Ross's model(36) and the DPM for grief(40).

Figure 7 - Diagrammatic Representation of Grief Models with Parent Quotations



6.1.2 EXAMINING LIVED EXPERIENCES OF NICU STAFF

This section will discuss the results of hermeneutic phenomenological study of lived experience of NICU staff of newborn death. Although the main focus of this thesis is parental experiences, a comprehensive understanding cannot be gained without engaging with

understanding the staff's experiences, beliefs, and efforts. Five NICU nurses and three doctors of varying years of experience were interviewed. It was important for me to understand the lived experience of doctors, as they are under-represented in the neonatal literature. The over-representation of nurses may be due to the nature of parent-staff relationships in the NICU as well as the size of nursing team(100). The analysis of data revealed a phenomenon of, 'creating an optimal experience for parents'. The four themes and nine sub-themes were relatively consistent with previously published literature highlighting the priorities and efforts of NICU staff in caring for seriously ill newborn babies and supporting parents in this process. The interpreted phenomenon presents a novel contribution to our understanding of the staff's lifeworld, which is the implicit coping mechanism underplay as they endeavoured to provide optimal care to the newborn baby's parents.

Facilitating parent-baby closeness- The importance of parent-infant closeness is well documented in the literature. Some of the long-term outcomes include baby's neurological development, social interactions, and ability to cope with stress(228, 229). However, in extremely sick and ventilated babies, it is often challenging to facilitate physical closeness. NICU nurses play a key role in determining the amount of physical engagement parents have with their newborn baby, further affecting the development of a parent-infant bond(229-231). Nurses acknowledged the need for facilitating parent-baby closeness despite the restrictions brought in by baby's critical condition and the NICU environment and supporting parents in achieving proximity, wherever possible.

Communication and tailored support to parents- All staff in the study reiterated the importance of providing tailored and comprehensive family support to parents in the NICU. In the past decade, Family Integrated Care (FIC) has received increasing attention to foster parent-infant closeness, parental involvement in infant's care as well as empowerment(232-234). In an endeavour to promote parental involvement and build relationships, staff talked about the importance of getting to know each parent and responding to their needs. Throughout this process, communication played a pivotal role. Several studies have shown the impact of

adequate parent-staff communication on parental stress levels(235-237). They understood the importance of consistent communication but also shared the challenges, especially in the wake of staff rotation. There is ample evidence to show the negative psychological impact when parents receive conflicting information or different opinions from different providers(78, 238-241).

Emotional impact of newborn death- There is also a considerable number of stressors that impinge upon NICU staff when working with babies with poor prognosis(53, 242). Feelings of conflict, guilt and feebleness take over for staff when they are unable to prevent death(243, 244). Emotional attachment with the baby is inevitable and the everyday life of NICU staff and training may not be sufficient to prepare them to deal with the death of a newborn baby(244, 245). Moral distress is experienced in the event of prolonged and aggressive treatment that is regarded as unnecessary by the medical team(51, 246, 247). Almost all staff who participated in the study did not find the counselling support offered by the hospital useful. To deal with the psychological impact of death, staff often resort to personal means to cope optimally(244), and this was applicable in this study as staff preferred personal avenues that ranged from the spiritual to peer support.

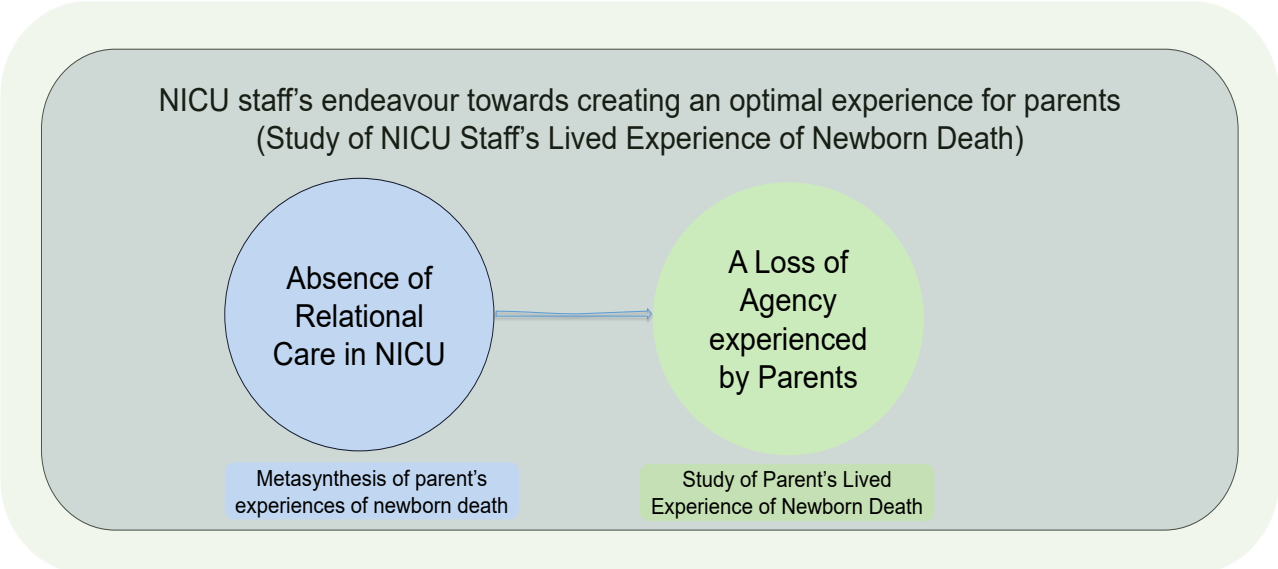
Overall, NICU staff endeavoured to create an optimal experience for parents and supporting them to the best of their abilities, within the situational constraints. While the study results may be consistent with the previously published research, the interpreted phenomenon makes a contribution to knowledge, which is the implicit coping mechanism for the NICU staff as they endeavoured to provide the best possible care and support to the newborn and his/her family during their newborn baby's death. In addition to the sense of accomplishment that staff experienced providing an optimal experience to parents also brought them the strength to power through the distress and anguish caused by the newborn baby's death. Another insight from the study is the influence of temporality and nature of newborn death on staff's lived experiences. NICU staff members were affected by the nature of death i.e. whether it was *expected* (gradual deterioration) or *unexpected* (sudden). It influenced their communication

and interpersonal engagement with parents as well as the emotional impact and moral distress experienced by staff. Moreover, it impacted on their ability to cope with a newborn baby's death due to the lack of preparedness in *unexpected* scenarios. Medically, with the advancements in neonatal intensive care and the ability to 'prolong life' almost indefinitely, there may not be any unexpected deaths in the NICU. However, all the staff interviewed in the study consistently shared the role played by this temporality and therefore it occupies a central positioning in the narrative. This is a novel finding and despite the extent of its influence over staff's experiences, it has not been studied within these dualities before.

6.2 AN INSIGHT INTO THE COMPREHENSIVE EXPERIENCE OF PARENTS AND NICU STAFF AROUND NEWBORN DEATH

An overarching phenomenon of this thesis is that despite staff's intent and their efforts to create an optimal experience for parents in NICU, an absence of relational care contributed to parents' experiencing a loss of agency (see figure below).

Figure 8- Diagrammatic representation of thesis's overarching phenomenon



Parents' time in the NICU around their newborn baby's death proved to be one of the most disempowering experiences of their life. As the data in this thesis has showed; despite the time since their bereavement, parents still battled with their new identity where they lacked a voice and advocate. The present study, therefore, highlights a clear disjunction between the lived experiences of the two groups and calls for efforts to guide NICU staff in supporting parents as they undergo the most challenging period of their lives. The previous sections have described the findings of the study in relation to the lived experiences of parents and staff around newborn death. The section below discusses the themes highlighting the commonalities in experiences of parents (from metasynthesis and lived experience study) and staff with an aim to generate a comprehensive understanding into the holistic experience of a newborn baby's death in the NICU.

Loss of control and inter-personal engagement- NICUs are neither a normal nor a familiar environment for people who have rarely or never had any health complications. Whether the pregnancy was complicated or healthy, admission of the newborn baby to a NICU was a disruptive life event for parents in the metasynthesis as well as lived experience study. Becoming a NICU parent and learning to interact with NICU Staff is an adaptive and challenging process for all parents. Emotionally and mentally, they entered a dynamic process of adopting communication and behavioural strategies to be able to secure the best care they want their baby to receive. They perceived that being cordial with staff was the pathway to ensure that their baby received the best care in the NICU. Knowingly or unknowingly, in this process, they ended up relinquishing their agency and control to the NICU environment. While parents often undergo a self-censorship on one side, the NICU staff, on the other hand, have the power to decide and determine the level and type of communication with parents. They regulate the intensity and frequency of the communication and engagement they have with parents(248) and therefore, occupy a significant control over situational autonomy. This was evident in parent's accounts. The metasynthesis reported parents expecting more time with the doctors to establish clearer channels of communication, and in the lived experience study,

parents were afraid of seeming needy and being perceived as difficult. Ineffective communication has been a consistent finding throughout this thesis. Previous studies have noted that care provided by healthcare professionals has the potential to make patients feel helpless by not focussing on them as a “whole” person(249). Although this finding was not specific to a NICU situation, it was evidently applicable in this study. Incognizant of the agency loss experienced by parents, NICU staff’s lack of focus on parents as a “whole” person contributed to the neglect and alienation experienced by parents. It manifested in their inability to speak and to *fully express* themselves. A study from the field of oncology demonstrated how patients who were at the end of life valued the ability of their medical team to oscillate between providing emotional support, acknowledgement of their suffering, and information and guidance based on their clinical expertise(250). While parents did want information and clarity on their newborn baby’s condition, they also needed and appreciated simple gestures of kindness and empathy from their doctors and nurses. The underlying phenomenon of compassionate care highlighted by the metasynthesis, as a key tenet and core value of inter-personal engagement in NICU remains relatively an under-explored phenomenon. Having this understanding of parental processes is important for NICU staff because communication and inter-personal engagement were the key factors in determining and influencing the lived experiences of parents.

There was a repeated emphasis on importance of providing tailored support to grieving parents in staff narratives. However, there was no mention of how tailored and individualised support was delivered to parents. There was a high level of dissatisfaction expressed by parents in the present study about the nature of communication and inter-personal engagement that they experienced in the NICU. Until recently there was also a gap in the literature on what it exactly meant by tailoring communication to parental needs. A systematic review has introduced a new theoretical framework for family-centred care and tailored communication in NICUs(245). By aggregating evidence from a wider group including parents, NICU staff, researchers, and FIC experts, the study suggests, that in order to attain adequate

staff-parent interaction, staff must pay attention to the “topic, aim, location, route and design” in every given situation of their communication with parents(245). Therefore, to ensure tailored communication, NICU staff may need to understand parental situatedness and to respond accordingly.

Understanding grief to support parents- Given the complexities and uncertainties involved, parental needs in the NICU are likely to be constantly changing. In addition to their unique needs, NICU parents also have different responses and reactions to their grief. Grief does not necessarily occur with death. The study confirmed that parents experienced grief prior to death. The metasynthesis explored the emotional impact of parent’s separation from their baby as well as their struggle with decisional conflict. Along with their grief, parents found it traumatic to see their child in pain and suffering but could not fathom making a decision that would end his/her life. In the lived experience study, grief was evident in every aspect of parent’s NICU life. There is also previously published evidence to show that it can co-exist with all phases, starting from admission to the NICU, to a loss of a normal newborn experience or control over their parenting(251).Therefore, managing emotional conflicts, facilitating preparedness and providing timely and appropriate supportive care to parents throughout the NICU stay is essential in managing their grief and its downstream effects. A survey-based study covering 200 NICUs in the UK pointed towards deficiencies in theoretical knowledge and practical training on neonatal bereavement care(252). Only 13% of the 330 staff who participated in the survey had any awareness of grief theories(252). While subscription to a particular theory is not key, knowledge of background theory may help the staff in understanding parental needs, different grief reactions, as well as be to identify the different types of losses that parents may experience. Although NICU nurses are frequently present during situations involving different stages of parental grief, they often lack the knowledge to understand the subjectivity of experience(253) and the skills to provide the care that parents require(254). In the lived experience study, parents found it helpful when they could talk about their grief, their emotions, insecurities, and their worries. Although seldom, they appreciated it

if staff gave them an opportunity to talk about their feelings, their fears and hope. In these moments they felt cared for and supported.

Pathway to transformation- Loss of old self was reported. Parents were no longer their same self they were prior to their newborn baby's birth and death. Although it was a societal expectation, a transition to their 'normal' life was deemed as not possible by the parents interviewed in the study. However, they required assistance as they tried to transform and reconstruct their lives after bereavement. A systematic process to support and guide parents in this endeavour is needed. An important, yet simple requirement from parents is to "get to know" them and understand their needs on an individual level(255). Bereavement support did not emerge as a key finding in the metasynthesis, as all studies explored specific aspects of newborn death and NICU (predominantly around decision-making and withdrawal of LST). However, in the lived experience study the bereavement support available for all parents was sporadic and they were often left on their own to find support for themselves. In absence of support, bereaved parents may not only lose its protective effects, but are also left vulnerable to worsening of grief, abandonment and deprivation(256). Complicated grief has been observed among parents bereaved from newborn death due to persisting grief symptoms, associated with poor physical and mental health, even after 6 months of the death(257). The perceived disrespectful behaviour from staff, neglect experienced by parents, absence of non-judgemental support and validation of the loss, have the potential to complicate their grief and push it towards disenfranchisement, thereby making their transformation process of adjusting to the new life even more challenging.

6.3 STENGTH AND LIMITATIONS

A number of strengths were evident in the study, which are highlighted in this section. Some limitations were also identified, which will also be outlined.

6.3.1 THE STRENGTHS

- This study is an original study. To the best of my knowledge, there is no study conducted in the UK that comprehensively captures voices and experiences of mothers, fathers, NICU doctors and nurses who have experienced newborn death. The main strength of this study is that parents and staff were asked to give an account of their experience in the NICU and of newborn death. There is a significant volume of literature on neonatal bereavement in the UK, however, these are always related to specific aspects of parental and staff experiences, such as end-of-life care, or decision-making and withdrawal of LST, or pre-term birth and bereavement. The use of Heideggerian phenomenology as the theoretical background for the study allowed me to approach participants without any pre-determined theories or concepts for questioning and provided an opportunity for me to explore the phenomenon of newborn death as lived and experienced by participants.
- The central thesis phenomenon of, 'an absence of relational care contributing to loss of agency experienced by parents, despite the efforts from staff to create an optimal experience for parents', is a contribution to knowledge. It provides a unique perspective to understand the NICU lifeworld created and experienced by participants (both parents and staff), which should further guide efforts to develop pragmatic supportive programmes for grieving parents and training for staff.
- Ethnic and racial diversity were achieved in the mother's group, which aids a broadening of our understanding on the potential impact of socio-cultural influences on grief and bereavement. This is an under-explored area, and this study aids our understanding of complexities perceived and experienced by mothers from diverse ethnic and racial backgrounds.
- The hermeneutic style of interviews and study enabled highlighting of a structural barrier faced by parents around the birth and death registration of the baby, which has not been identified previously in terms of bereavement support that should be made

available for parents. Another contribution of the methodology was the lack of parental focus on withdrawal of LST. Ethical issues, decision-making and withdrawal of LST occupy a significant proportion of published literature in newborn death and bereavement, something that was evident in the metasynthesis as 12 out of 20 studies focussed on issues related to decision-making and withdrawal of LST. However, when parents were provided a platform to craft their own narrative of NICU experiences, withdrawal of LST and surrounding issues were not mentioned. This is an important finding that points towards a gap between research priorities and parental experiences and re-establishes the importance of an exploratory phenomenological enquiry into lived experiences of parents bereaved from newborn death.

- Participant narratives were captured with in-depth interviews that were digitally recorded, transcribed verbatim and interpreted and analysed by me to ensure consistency. Reflexive process was maintained with regular journaling. A personal testimony of experience from both parents and staff is the real strength of this study. Parents treated the interviews and the study as a medium for extending their child's memory, sharing their grief, and reflecting on their bereavement experience without any inhibitions. They appreciated the platform to speak without any societal complexities involved. An absence of the fear of being judged and their grief not being given the deserved significance, allowed them to speak candidly and share unfiltered accounts of their experience. Moreover, due to the hermeneutic nature of and the free-flowing style of interviews (without prescriptive aspects and concepts) allowed parents to weave their own story and narrative and allowed me an unreserved access to their lifeworld.

6.3.2 THE LIMITATIONS

- The findings from this hermeneutic phenomenological study are valuable and add to the current body of knowledge. Experiences of participants may or may not be similar to other parents and staff who experience newborn death. However, the study gives

us an in-depth insight into the participants' lifeworld and advances our understanding of bereavement from newborn death to design better care and support mechanisms.

- Recruitment to the study relied upon individuals volunteering to participate after receiving information about the study. As a result, only those who were willing and wanted to share their experiences constitute the sample of the study. Bereaved parents for whom the experience was still very raw or prominent, may have produced different type of narrative, which the study did not have access to. Similarly, participants, such as separated/divorced parents or fathers from diverse ethnic and racial backgrounds, who chose not to participate may have had differing experiences and therefore their voices are under-represented. Efforts were made to reach out to a diverse group of parents and create awareness of the study and encourage participation. While diversity was achieved for mothers, only fathers identifying as White-British agreed to participate in the study. Moreover, only four fathers volunteered to participate in the study. It is presumed that the societal expectations from fathers to remain *strong* for their families restrict them from sharing their grief and experiences. Although, a phenomenological study does not mandate a large sample size, more numbers of fathers interviewed in the study would have given additional insight into fathers' experiences of NICU and newborn death.
- Upon the suggestions of parent representatives, the inclusion criteria were expanded to include bereaved parents irrespective of the time since their newborn baby's death. Therefore, for some parents the time frame of bereavement was more recent in comparison to others. This may have aided a more reflective account to narratives of some parents.
- Due to the voluntary nature of recruitment, no male NICU staff member was interviewed in the study. Although, I do not consider this as a limitation of the study, it may have been interesting to explore views and experiences (if any) in terms of gender differences. Moreover, one may argue that the staff were recruited only from three NICUs and therefore may not be representative of experiences of larger workforce. To

address this concern, I have presented the study findings to the neonatal network at NHS England Southeast, including the Kent, Surrey & Sussex (KSS) Neonatal Operational Delivery Network, Bereavement care- Postgraduate Forum at Imperial College NHS Trust, locally based charities including SANDS, as well as at larger international platforms. This has been clear from the discussions that have occurred because of the presentations, which indicated that other neonatal staff share similar views and experiences. More importantly, with the KSS network and parallelly with collaborators at SANDS charity, there are discussions underway on how to incorporate the study findings and recommendations (see section 7.1) into practice and aim for wider dissemination.

- Finally, due to my linguistic limitations, only participants comfortable with English were recruited, which may have excluded voices of some of the more marginalised groups in society.

6.4 CONCLUSION

The aim of the study was not to juxtapose the experiences but to understand the phenomenon of newborn death as experienced by parents and NICU staff. This discussion chapter has synthesised the overall findings of the study on lived experiences of parents and NICU staff who experienced newborn death in context of published literature, as well as highlighting new areas of knowledge. A critical application of some of the major grief theories and key concepts with parental experiences were discussed followed by a comprehensive insight into the wholistic experience of newborn death. The chapter is concluded with a discussion of study strengths and limitations.

CHAPTER SEVEN- CONCLUSION, RECOMMENDATIONS AND CLOSING REMARKS

7.0 INTRODUCTION

This study has elicited the lived experiences of parents of newborn death and bereavement and of NICU staff providing care to the admitted newborns and working with bereaved parents in this process. The aim of this thesis was to, (a) offer an in-depth account of parents' experiences of newborn death in the UK, within the context of the clinical encounter, understanding the emotional and personal accounts of parents, while in the NICU and after, and their process of bereavement and grief, and (b) to better understand views and beliefs of NICU staff (both doctors and nurses), about newborn death and their experiences of working with parents, with the goal of identifying opportunities for improved support for parents. The study findings have demonstrated fulfilment of the aims and objectives (see section 1.5 for detailed list of objectives). The overall study design, explored in chapter 3, allowed for the capture of detailed accounts and narrative of parents and staff and thereby enable a comprehensive understanding of the phenomenon of newborn death.

This is the final chapter of this thesis, which presents the study's main contribution to knowledge, the recommendations for practice and research. Thereafter, it draws upon my research journey and concludes the thesis.

7.1 CONTRIBUTION TO KNOWLEDGE

The main finding and overarching phenomenon of this thesis is that, 'despite the efforts from staff to create an optimal experience for parents, an absence of relational care in the NICU contributed to a loss of agency for parents.' These findings provide a novel contribution to knowledge. This is the first time a study was conducted in the UK to develop a comprehensive and wholistic understanding of the phenomenon of newborn death from the lived experiences of bereaved parents and NICU staff. More specific contributions made to knowledge from this study are presented as follows:

- The metasynthesis discussed the importance and need for physical contact between the parents and baby in the NICU. It highlighted the gap in extending this recognition as the baby transitioned from being alive to their subsequent death. Metasynthesis contributed the new perspective to recognise and facilitate the transcendental needs of parents for physical and emotional closeness with their baby.
- The metasynthesis contributed to our understanding that an absence of relational and personalised care creates a misalignment between staff and parents leading to a soured experience for all involved. It highlighted how a well-intentioned but paternalistic endeavour to protect parents from guilt and suffering, sometimes results in a withdrawal of parental autonomy and staff-parent conflicts.
- It is known that parents experience disempowerment in the NICU environment. However, what is original is the phenomenon of loss of agency illuminated by the study, the extent of this experience and the impact of it on parents' bereavement journey and long-term grief. Disregard and neglect experienced by parents, that contributed to their agency loss, had a spiralling impact on their grief and coping process.
- The lived experience study highlighted how some mothers compared their NICU experiences with the cultural subjugation of women in some other parts of the world.

As discussed previously in section 6.1.1, there has been recent evidence of cultural disparity in maternal and neonatal care in the UK. However, an insight into the lifeworld of mothers as they compared the impact of historical cultural oppression with their NICU experiences is an important, yet novel, addition to our understanding.

- The emotional turmoil experienced by parents due to the task of having to register birth and death of the baby together was highlighted by this study. Parents were inadequately supported by the NICU staff and were not counselled regarding the need for such a task. Parents did not expect this juxta-positioning of birth and death registration, and while they acknowledged that this was a task that needed to be completed, the lack of mental preparedness multiplied the intensity of emotional impact.
- This study has brought to attention the prescriptive nature of bereavement counselling offered to parents. The communication and engagement with bereavement counsellors was perceived to be unhelpful by parents. Parents experienced a societal disregard of their grief when they were expected to move on quickly. They described how they felt their newborn baby's death, and their grief was insignificant for others. Not having the required bereavement support was isolating for parents and contributed towards what felt like depriving them of their right to grieve.
- The nature of a newborn baby's death i.e. whether it was *expected* or *unexpected* is a unique addition from this study to understanding staff's experiences. Medically, this categorisation may be technically incorrect, as almost all deaths in the UK now occur by withdrawal of LST in the NICU (3, 4), which indicates that all deaths in NICUs may be 'expected'. However, as discussed in section 3.1.2.2 on Heidegger's interpretive phenomenology, the focus of a hermeneutic study is not what we know, but what is experienced and what is the interpretation of that experience. It is therefore important to look beyond concepts and engage with the meanings that influence lived

experiences of individuals. This study highlights the role played by *expected* and *unexpected* nature of newborn deaths in staff's lived experience. These differences in the type of newborn death influenced the way NICU staff counselled and supported parents. It impacted their communication and inter-personal engagement with parents as well as the emotional impact of newborn baby's death on staff.

- With each experience of a newborn baby's death in the NICU, staff described feeling emotional impact. This study provides a valuable insight that prioritising optimal and the best possible care and support for parents is an implicit coping mechanism deployed by staff to protect themselves from experiencing emotional anguish. It helps them find meaning in their role as a care provider and the motivation to move forward with their responsibilities.

7.2 RECOMMENDATIONS

The study findings highlight that despite the efforts of a well-intentioned NICU team in creating a caring and supportive environment for grieving parents, loss of agency was experienced. As a result of this study's findings and critical contributions to knowledge, a few recommendations can be made for practice and research.

7.2.1 RECOMMENDATIONS FOR PRACTICE

- One of the key aspects towards empowering and integrating grieving parents in the NICU should be by allowing and encouraging them to share their feelings without any inhibitions of feeling judged. Parents must not be made to feel that sharing their concerns or raising any questions might impact the care their baby receives in the NICU. Staff can support parental participation during NICU rounds by encouraging parents to share how they view and understand their child's condition. In doing so,

parents may be able to express their understanding as well as their questions. This will further allow staff to develop an understanding of parent's situatedness and respond accordingly with verbal as well as non-verbal gestures. Providing parents with a comfortable space and atmosphere to share their vulnerabilities has the potential to prevent the disempowerment and loss of agency that parents in this study experienced in the NICU.

- This study found that NICU staff had an important and crucial role in influencing parental grief and bereavement from newborn death. Evidence has shown that although there is no formula to mitigate the grief, it is possible to support people by reassuring them that they are not alone (212, 258). As suggested by the study, individual mothers and fathers may grieve differently following their baby's death. The contextualised nature of grief emphasises the importance of targeted and flexible support options, to assist mothers and fathers process their grief and feel validated, acknowledged, and supported. It is important that staff are trained on grief reactions observed by parents in anticipation and presence of death and therefore, can offer adequate support to parents in identifying effective coping strategies during their time in the NICU.
- The inadequate nature of organised and systematic support in the NICU as well as after, presents an opportunity to explore gaps in service to bereaved parents of the NICU. Parents in the study found that the counselling sessions offered to them were very prescriptive in nature. It was felt that this was completely in contrast to their needs and expectations. What parents needed was to be *heard* rather than be *told* what they should do and how they must reorganise their life. It is an important area that needs to be addressed in practice. It is recommended that bereavement counselling programmes are revisited to acknowledge the gaps, and refresher training is provided to practitioners rooted in this study's findings on parental lived experiences.

Additionally, focussed efforts must be made to increase bereavement support available for fathers, and ensure avenues are made available to them to share their grief and access support independent of their partners and families.

- It is difficult for NICU staff to identify grief based on the outward symptoms and identify risk factors of complicated grief. Therefore, a recommendation for practice could potentially include identifying and screening at-risk parents during the NICU hospitalisation as well as during bereavement follow-up meetings. Timely identification will allow enhanced understanding of parental needs, as well as their situatedness, and thereby tailor care and support for individualised needs and experiences.
- The study found that being unprepared for the possibility of a juxta-positioning of birth and death registration made the experience traumatic for parents. Although it was an administrative task, parents were unprepared, and the unexpected nature of the task made the experience difficult for parents. It is recommended that this aspect of birth and death registration be included in the bereavement support provided in the NICU. Parents must be counselled beforehand, and efforts should be made to extend support in handling the task if required by parents.
- All the staff who participated in the study did not regard the counselling support offered by their NHS Trusts as helpful in managing the emotional impact of newborn deaths. They preferred informal sources of support, especially from their peers. This is an important finding for the management of NHS resources. It is recommended that it is revisited to further understand the need, uptake, and utilisation of support services.

An overarching recommendation from this thesis is the need for NICU staff's training on working with and supporting grieving parents, which must be based on the powerful narratives of parents presented in this study.

7.2.2 RECOMMENDATIONS FOR RESEARCH

- This study found women reported stigma (both real and perceived) that contributed to their isolation in a time of great need. It added to the complexities in grief and potentially contributed to the feeling of marginalisation experienced by women culturally. It is recommended that cultural stigma and isolation in NICUs is further explored in-depth using an appropriate qualitative methodology such as grounded theory.
- Structural challenges and hinderances (such as staff rotation) in ensuring consistency of communication were highlighted by staff. The psychological impact of this inconsistency in communication was recounted by most parents and echoed by staff in terms of breakdown of staff-parent trust. This is an important area that needs to be addressed with participatory research and stakeholder engagement and thereafter, implemented in practice.
- Finally, it is recommended that the role of temporality and nature of newborn baby's death on staff's lived experiences is explored further. It is important as it affected how staff communicated, counselled, and engaged with parents, and may highlight avenues of improving parent-staff relationship and inter-personal engagement.

7.3 A REFLECTIVE ACCOUNT OF MY RESEARCH JOURNEY

This thesis offers a unique exploration of parental and staff experiences of newborn death and the emergent phenomena. As I near the conclusion of this journey, I will take this opportunity to briefly share a reflective account of my research journey. At the outset of this study, and in congruence with the methodology, I commenced a reflective journal which not only recorded the research process but also the emotional journey I undertook. What started as eagerness to understand the underlying reasons behind conflict between parents and staff, became an all-consuming and emotionally draining experience for me. While the nature of the study was

already intense, my personal life journey of pregnancy, giving birth and becoming a parent added to the unanticipated emotional complexities. Now, I had relativity and personal experiences of complications at birth and uncertainty of outcome. As I engaged with personal and heart wrenching accounts of parents I remembered my own journey, which made the process more difficult. Listening to audio recordings multiple times, reading and re-reading the transcripts was a constant emotional battle for me. While I was grateful for my healthy and prospering child, I became extremely empathetic to the losses experienced by my study parents. As a result of changes in my fore-structures and positionality, I realised the increasing importance of the reflexive journal and its role played in the analysis journey. Although this self-awareness was challenging, engaging with my situatedness enabled me to interact even more deeply with the data and allowed a total immersion in the study. More than anything I am grateful for all the parents who participated in my study and allowed me access to their lifeworld, which further allowed me to explore their situatedness and ontological perspectives, which was the focus of the study.

The main problem I encountered in the research journey was accessing parents to participate in the study through the gatekeepers who were understandably protective. To overcome this, the recruitment strategy was modified and expanded to include wider reach through charity organisations such as SANDS. As this is a phenomenological study, the data generated from a small size was very rich in nature. It has been a constant struggle for me to try and do the narrative justice. With constant support from my supervisors, my interview and analysis skills improved with time. Understanding Heideggerian philosophy was a difficult task, and without Van Manen's guidance(163) on the engagement with 'circle of understanding' it would have been a difficult task to achieve. Overtime as my understanding progressed, I devised my own process of analysis by engaging and re-engaging with my data and my pre-conceptions. I do believe that my background and experiences have guided and enabled me to reach a much deeper understanding of the lived experiences. My horizons fused with those of the

participants, especially parents, enabling me to reach an interpretive understanding which I believe does justice to their stories.

7.4 CONCLUSION OF THESIS AND CLOSING REMARKS

Throughout this thesis I have focussed on the lived experiences of parents and staff of newborn death. The study has been able to highlight the complexities of experiences in the NICU surrounding a newborn baby's death and brought to the forefront certain key areas that require attention of researchers and practitioners. Death of a child is the most devastating experience for any parent and efforts must be made to ensure this devastation is not multiplied due to lack of understanding and incongruity between parental needs and efforts of well-intentioned NICU staff. I hope this study can contribute towards supporting parental grief and the bereavement journey and creating a supportive atmosphere for NICU staff to provide most optimal care and support for parents. Personally, I have gained a lot from this study. Not only has it been an inspiring journey, but also increased my knowledge enormously and given me confidence in my abilities as a researcher. In conclusion, I believe this study has contributed vital knowledge and insights to parents and NICU staff's experiences of newborn death, which can be used to inform future research and practice.

RESEARCH OUTPUT

List of Publications related to the thesis

1. Pant S, 2021, Ethical issues around death and withdrawal of life support in neonatal intensive care, Indian Journal of Pediatrics, ISSN:0019-5456

Conference and Poster Presentations related to the thesis

1. Absence of Relational Care: A Metasynthesis of Qualitative Research in Parental experience of bereavement. Pediatric Academic Society, May 2024, Toronto, Canada (Accepted for Oral Presentation)
2. Living Through a Loss of Agency: A Hermeneutic Phenomenological Study. Pediatric Academic Society, May 2024, Toronto, Canada (Accepted for Poster Presentation)
3. An interpretive phenomenological enquiry into parents' lived experiences of bereavement and newborn death Poster presentation. Inaugural PaeCH Science Day, Imperial College London, 12 July 2023

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APPENDIX 1- METASYNTHESIS SEARCH STRATEGY

1- DATABASE- CINAHL

S1. AB Experience*
S2. AB “Perspectives”
S3. MH “Decision making”
S4. MH “Attitude to death”)
S5. (AB Experienc*) OR (AB “Perspectives”) OR (MH “Decision making”) OR (MH “Attitude to death”)
S6. MH “mothers”
S7. MH “fathers”
S8. MH “Parents”
S9. AB Parent*
S10. (MH “mothers”) OR (MH “fathers”) OR (MH “Parents”) OR (AB Parent*)
S11. MH “Perinatal death”
S12. MH “infant death”
S13. MH “bereavement”
S14. MH “grief”
S15. AB “newborn death”
S16. MH “newborn infant”
S17. MH “Death”
S18. (((((((Perinatal death[MeSH Terms]) OR (infant death[MeSH Terms])) OR (bereavement[MeSH Terms])) OR (grief[MeSH Terms])) OR (infant[MeSH Terms])) OR (newborn[MeSH Terms])) OR (death[MeSH Terms])) OR (“newborn death”[Title/Abstract])
S19. MH “Intensive care units”
S20. MH “neonatal intensive care units”
S21. MH ICU
S22. MH NICU
S23. (MH “Intensive care units”) OR (MH “neonatal intensive care units”) OR (MH ICU) OR (MH NICU)

S24. MH “Qualitative studies”
S25. AB “mixed methods”
S26. (MH “Qualitative studies”) OR (AB “mixed methods”)

S27 #S5 and #S10 and #S18 and #S23 and #S26

2- DATABASE- PubMed

#1 Experience*[Title/Abstract]
#2 Perspectives[Title/Abstract]
#3 Decision making [MeSH Terms]
#4 Attitude to death[MeSH Terms]
#5 (((experienc*[Title/Abstract]) OR (perspectives[Title/Abstract])) OR (decision making[MeSH Terms])) OR (attitude to death[MeSH Terms])
#6 Mothers [MeSH Terms]
#7 Fathers [MeSH Terms]
#8 Parents [MeSH Terms]
#9 Parent*[Title/Abstract]
#10 (((mothers[MeSH Terms]) OR (fathers[MeSH Terms])) OR (parents[MeSH Terms])) OR (parent*[Title/Abstract])
#11 Perinatal death [MeSH Terms]
#12 Infant death [MeSH Terms]
#13 Bereavement [MeSH Terms]
#14 Grief [MeSH Terms]
#15 Newborn death[Title/Abstract]
#16 Infant[MeSH Terms]
#17 Newborn[MeSH Terms]
#18 Death [MeSH Terms]
#19 (((((((Perinatal death[MeSH Terms]) OR (infant death[MeSH Terms])) OR (bereavement[MeSH Terms])) OR (grief[MeSH Terms])) OR (infant[MeSH Terms])) OR (newborn[MeSH Terms])) OR (death[MeSH Terms])) OR (“newborn death”[Title/Abstract])
#20 Intensive care units[MeSH Terms]
#21 Neonatal intensive care units [MeSH Terms]
#22ICU [MeSH Terms]
#23 NICU [MeSH Terms]
#24 (((neonatal intensive care units[MeSH Terms]) OR (intensive care units[MeSH Terms])) OR (ICU[MeSH Terms])) OR (NICU[MeSH Terms])
#25 Qualitative research[MeSH Terms]
#26 “Mixed methods” [Title/Abstract])
27 Search: ((qualitative research[MeSH Terms])) OR ("mixed methods"[Title/Abstract])
#28 (experienc*[Title/Abstract]) OR (perspectives[Title/Abstract]) OR (decision making[MeSH Terms]) OR (attitude to death[MeSH Terms]) AND mothers[MeSH Terms]) OR (fathers[MeSH Terms]) OR (parents[MeSH Terms]) OR (parent*[Title/Abstract]) AND (Perinatal death[MeSH Terms]) OR (infant death[MeSH Terms]) OR (bereavement[MeSH Terms])) OR (grief[MeSH Terms]) OR (infant[MeSH Terms]) OR (newborn[MeSH Terms]) OR (death[MeSH Terms]) OR (“newborn death”[Title/Abstract]) AND (neonatal intensive care units[MeSH Terms]) OR (intensive care units[MeSH Terms]) OR (ICU[MeSH Terms]) OR (NICU[MeSH Terms]) AND (qualitative research[MeSH Terms])) OR ("mixed methods"[Title/Abstract]) Filters: English

3- DATABASE- PsycInfo

1. Experienc*.mp.
2. Perspectives.mp.
3. Exp Decision making/
4. Exp Death Attitude/
5. 1 or 2 or 3 or 4
6. Exp Mothers/
7. Exp Fathers/
8. Exp Parents/
9. Parent*m.p.
10. 6 or 7 or 8 or 9
11. Perinatal death.mp
12. Infant death.mp.
13. Exp Bereavement/
14. Exp Grief/
15. Newborn death .mp.
16. Infant.mp.
17. Newborn.mp.
18. Exp Death and dying/
19. 11 or 1 or 13 or 14 or 15 or 16 or 17 or 18
20. Exp Neonatal intensive care/
21. Exp Intensive care/
22. Exp ICU/
23. 20 or 21 or 22
24. Exp Qualitative methods/
25. Mixed methods.mp
26. 24 or 25
27. 5 and10 and 19 and 23 and 26

4- DATABASE- Scopus

1. Experienc*
2. Perspectives
3. “Decision making”
4. “Attitude to death”
5. Experience* OR perspectives OR “Decision making” OR “Attitude to death”
6. Mothers
7. Fathers
8. Parents
9. Parent*
10. Mothers OR fathers OR parents OR parent*
11. “Perinatal death”
12. “Infant death”
13. Bereavement
14. Grief
15. “Newborn death”
16. Infant
17. Newborn
18. Death
19. “Perinatal death” OR “Infant death” OR Bereavement OR Grief OR “Newborn death” Infant OR Newborn OR Death
20. “Neonatal intensive care units”
21. “Intensive care units”
22. ICU
23. NICU
24. “Neonatal intensive care units” OR “Intensive care units” OR ICU OR NICU
25. “Qualitative study”
26. “Mixed methods”
27. “Qualitative study” OR “Mixed methods”
28. Experience* OR perspectives OR “Decision making” OR “Attitude to death” AND Mothers OR fathers OR parents OR parent* AND “Perinatal death” OR “Infant death” OR Bereavement OR Grief OR “Newborn death” Infant OR Newborn OR Death AND “Neonatal intensive care units” OR “Intensive care units” OR ICU OR NICU AND “Qualitative study” OR “Mixed methods”

APPENDIX 2- RESEARCH DESIGN SERVICE DECISION FORM

Research Design Service London

NHS National Institute for Health Research

PIF App ID: 345- Decision Form

PI / Contact Name and email: Stuti Pant s.pant@imperial.ac.uk

Name of RDS London Adviser supporting project: Ms Toqir K Mukhtar

Study Title:

Social and cultural influences on parental experiences around the time of newborn death

General Comments

An interesting study exploring the social and cultural influences on parental experience of the death of a newborn child.

Comments on proposed PPI activity

The applicant has rightly identified the need for robust PPI throughout this project and the sensitivities involved. Relevant parent groups have been identified and the applicant is being supported by a PPI officer at Imperial.

Comments on further PPI plans

The plans for involvement in the study appear reasonable.

PPI PIF costs: reasonable.

PIF decision: Favourable
Conditional
Unsuccessful

Ethical Alert – this Research & the PPI involves significant ethical issues relating to infant death. It is suggested that the applicant seeks input from the RDS Ethics Advisor via the General Advisors.

Imperial College London

Sands

Help us improve bereavement support by sharing your experience

We are working with researchers to understand the experience of parents whose baby died in the neonatal unit.

They want to speak with from parents of different social & cultural backgrounds & ethnicities about their experience of neonatal care & NHS bereavement support

To find out more please contact
Stuti Pant: s.pant@imperial.ac.uk

APPENDIX 4- PARTICIPANT INFORMATION LEAFLET- PARENTS

ALL IDENTIFIABLE INFORMATION INCLUDING HEADER AND LOGO REMOVED

PARTCIPANT INFORMATION LEAFLET

(Parents)

VERSION 2 (19.10.2021)

We would like to invite you to participate in this research project. This leaflet explains why the research is being done and what it will involve. Please take time to read the information carefully. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study and why are you inviting me?

Very little research has been carried out on the influence of culture and ethnicity on parental experiences around bereavement of their new-born child and with regards to various critical decisions around medical interventions in the intensive care unit. In this qualitative study, we want to speak with parents who have experienced new-born death recently. The responses will provide important insights into improving the experiences and bereavement support of families from diverse backgrounds undergoing withdrawal of life support and new-born death. We would like to hear from you about your experience and the journey. However, if at any point you do not wish to continue the conversation, please feel free to let us know and we will end the meeting.

Do I have to take part?

It is your choice whether you whether you want to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

If you decide to participate, an experienced qualitative researcher will conduct an in-depth interview with you regarding your experiences around the time birth of your baby and participating in this research study. This interview can be arranged in hospital, your home, another place you prefer or virtually, at a time that suits you. We would expect the interview to last around an hour. We appreciate that you may not remember the exact details. We will audio record the interview and you would be free to stop or pause the interview at any time.

The interview will be a little like a conversation, in which we will help you talk about yourself in your own words. We will ask you to talk about your experiences of bereavement. We will ask questions about what happened to you, what your thoughts and feelings have been at different stages, how you have got support and information, what you have done, and what you have found helpful, or not.

While people sometimes find it helpful to talk about their story to researchers this research is not the same thing as counselling. However, we can give everyone a list of useful contacts which can be used to get more help if you want.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

What are the possible benefits of taking part?

The study may not directly benefit you, but your views and experiences will provide researchers and healthcare professionals with very important information about the views and needs of bereaved parents. This also helps in planning the services provided.

You will not receive any monetary benefits/compensation for participating in the study.

What are the possible disadvantages and risks of taking part?

Some people find that thinking about their situation makes them upset or sad. If you feel unhappy about any part of the interview you can choose to break immediately or to stop altogether.

We will minimise the risk of data loss and breach of confidentiality by storing all data in approved and secure password protected server at Imperial College London.

What if something goes wrong?

Imperial College London holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you will be eligible to claim compensation without having to prove that Imperial College is at fault. This does not affect your legal rights to seek compensation.

If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way

you have been treated during the course of this study then you should immediately inform the Investigator (Name and Phone number). The normal National Health Service mechanisms are also available to you. If you are still not satisfied with the response, you may contact the Imperial College, Research Governance and Integrity Team.

What will happen to the results of the research study?

The learnings from the study will may be used by the research team to modify /improvise the process followed in the future. We will also publish the results of the study in medical journals and present at various medical conferences, so that other hospitals can also use this information to improve their services.

Quotations from the interviews may be used in publications, but you will never be identified in any publication. All the information we collect and use for analysis will be strictly confidential. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

General data protection transparency statement

Imperial College London is the sponsor for this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Imperial College London will keep your personal data for:

10 after the study has finished in relation to data subject consent forms.

10 after the study has completed in relation to primary research data.

We will need to use information from you for this research project. This information will include your name, name of the hospital your baby was admitted and the month and year of admission. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

LEGAL BASIS

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research

INTERNATIONAL TRANSFERS

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (EC) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

SHARING YOUR INFORMATION WITH OTHERS

For the purposes referred to in this privacy notice and relying on the bases for processing as set out above, we will share your personal data with certain third parties. Other College employees, agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third-party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED

For the purposes referred to in this privacy notice and relying on the bases for processing as set out above, we will share your personal data with certain third parties.

Other College employees, agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED

You can find out more about how we use your information

at www.hra.nhs.uk/information-about-patients/

by asking one of the research team

by sending an email to [email], or

by ringing us on [phone number].

COMPLAINT

If you wish to raise a complaint on how we have handled your personal data, please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.

Who is organising and funding the research?

The study will be run at several national sites. It is funded by the National Institute for Health Research. Imperial College London is the main sponsor. Doctors will not be paid for including you in the study, nor do participants receive payment.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by West of Scotland Research Ethics Committee.

Contact for Further Information

Please do not hesitate to ask if you have more questions.

Local Principal Investigator

APPENDIX 5- PARTICIPANT INFORMATION LEAFLET – NICU STAFF

ALL IDENTIFIABLE INFORMATION INCLUDING HEADER AND LOGO REMOVED

PARTCIPANT INFORMATION LEAFLET

(Professionals)

VERSION 2 (19.10.2021)

We would like to invite you to participate in this research project. This leaflet explains why the research is being done and what it will involve. Please take time to read the information carefully. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study and why are you inviting me?

Very little research has been carried out on understanding lived experiences of professionals in neonatal intensive care when faced with death of a newborn infant and with regards to various ethical dilemmas and decisions related to end of life care. In this qualitative study, we want to interview a few neonatologists and other medical staff who work in the neonatal units in the UK. Since you have experience of working in the neonatal intensive care unit, we feel that your experiences and views on this topic could add value to our research study.

Do I have to take part?

It is your choice whether you whether you want to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

If you decide to participate, an experienced qualitative researcher will conduct an in-depth interview with you regarding your experiences around the time death of baby and participating in this research study. This interview can be arranged in hospital, or another place you prefer, or virtually, at a time that suits you. We would expect the interview to last around an hour. We will audio record the interview and you would be free to stop or pause the interview at any time.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

What are the possible benefits of taking part?

The study may not directly benefit you, but your views and experiences will provide researchers with very important information about the views and needs of healthcare professionals who often experience death in their neonatal intensive care unit and work with bereaved parents. This also helps in planning the support provided.

You will not receive any monetary benefits/compensation for participating in the study.

What are the possible disadvantages and risks of taking part?

Some people find that thinking about such experiences makes them upset or sad. If you feel unhappy about any part of the interview you can choose to break immediately or to stop altogether.

We will minimise the risk of data loss and breach of confidentiality by storing all data in approved and secure password protected server at Imperial College London.

What if something goes wrong?

Imperial College London holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you will be eligible to claim compensation without having to prove that Imperial College is at fault. This does not affect your legal rights to seek compensation.

If you are harmed due to someone's negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Investigator (Name and Phone number). The normal National Health Service mechanisms are also available to you. If you are still not satisfied with the response, you may contact the Imperial College, Research Governance and Integrity Team.

What will happen to the results of the research study?

The learnings from the study will may be used by the research team to modify /improvise the processes followed in the future. We will also publish the results of the study in medical journals and present at various medical conferences, so that other hospitals can also use this information to improve their research consenting process.

Quotations from the interviews may be used in publications, but you will never be identified in any publication. All the information we collect and use for analysis will be strictly confidential. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

General data protection transparency statement

Imperial College London is the sponsor for this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Imperial College London will keep your personal data for:

10 after the study has finished in relation to data subject consent forms.

10 after the study has completed in relation to primary research data.

We will need to use information from you for this research project. This information will include your name, name of the hospital your baby was admitted and the month and year of admission. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

LEGAL BASIS

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research

INTERNATIONAL TRANSFERS

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (EC) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

SHARING YOUR INFORMATION WITH OTHERS

For the purposes referred to in this privacy notice and relying on the bases for processing as set out above, we will share your personal data with certain third parties. Other College employees, agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third-party service providers are required

to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED

For the purposes referred to in this privacy notice and relying on the bases for processing as set out above, we will share your personal data with certain third parties.

Other College employees, agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED

You can find out more about how we use your information

at www.hra.nhs.uk/information-about-patients/

by asking one of the research team

by sending an email to [email], or

by ringing us on [phone number].

COMPLAINT

If you wish to raise a complaint on how we have handled your personal data, please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.

Who is organising and funding the research?

The study will be run at several national sites. It is funded by the National Institute for Health Research. Imperial College London is the main sponsor.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by West of Scotland Research Ethics Committee.

Contact for Further Information

Please do not hesitate to ask if you have more questions.

Local Principal Investigator

APPENDIX 6- CONSENT FORM- PARENTS

ALL IDENTIFIABLE INFORMATION INCLUDING HEADER AND LOGO REMOVED

Consent Form for Participants Able to Give Consent (Parents)

VERSION 2 (19.10.2021)

I confirm that I have read and understand the participant information sheet dated 19/10/2021 version 2 for the above study and have had the opportunity to ask questions which have been answered fully.	
I understand that the my participation in this study is voluntary and that I am free to withdraw from the study at any time, without giving any reason, without the medical care or legal rights of being affected.	
I understand that sections of any of my medical notes may be looked at by responsible individuals from Imperial College London, where it is relevant to my taking part in this research.	
I give permission for Imperial College London to access my records that are relevant to this research.	
I give/do not give (delete as applicable) consent for information collected about me to be used to support other research in the future, including those outside of the EEA.	
I give / do not give (delete as applicable) consent for samples collected during this study to be used in future ethically approved studies. I give permission for my samples to be sent to other organisations, including these outside of the EEA	
I consent to take part in the above study.	
I give/do not give (delete as applicable) consent to being contacted to potentially taking part in other research studies.	
I consent audio recording of my interview	
I consent for my direct quotes to be used in publications without identification	

Name of Participant Signature
Date

_____ _____
_____

Name of Person taking consent Signature
Date
(if different from Principal Investigator)

_____ _____
_____

Principal Investigator Signature
Date

1 copy for participant; 1 copy for Principal Investigator

APPENDIX 7- CONSENT FORM – NICU STAFF

ALL IDENTIFIABLE INFORMATION INCLUDING HEADER AND LOGO REMOVED

Consent Form for Participants Able to Give Consent (Professionals)

VERSION 2 (19.10.2021)

I confirm that I have read and understand the participant information sheet dated 18/12/2020 version 1 for the above study and have had the opportunity to ask questions which have been answered fully.	
I understand that the my participation in this study is voluntary and that I am free to withdraw from the study at any time, without giving any reason, without the medical care or legal rights of being affected.	
I give permission for Imperial College London to access my records that are relevant to this research.	
I give/do not give (delete as applicable) consent for information collected about me to be used to support other research in the future, including those outside of the EEA.	
I consent to take part in the above study.	
I give/do not give (delete as applicable) consent consent to being contacted to potentially taking part in other research studies.	
I consent audio recording of my interview	
I consent for my direct quotes to be used in publications without identification	

Name of Participant	Signature	Date
_____	_____	_____
Name of Person taking consent (if different from Principal Investigator)	Signature	Date
_____	_____	_____
Principal Investigator	Signature	Date

1 copy for participant; 1 copy for Principal Investigator

APPENDIX 8- TENTATIVE TOPIC GUIDE – PARENTS

TENTATIVE TOPIC GUIDE: Parents' Experiences around newborn death

Introduction:

- *Before starting the interview, introduce yourself, explain the purpose of this research, share the information leaflet and consent form. Make sure the participant is comfortable, asking general rapport building questions*
- *Explain to the participant that there are no right or wrong answers, and the aim of this interview is to understand their experiences*
- *Explain confidentiality, use of recorder and data from the research*
- *Explain that in addition to the recording, you will be taking notes during the interview*
- *Check consent form for signature. Ask if any questions before starting the interview.*

Demographic details

Name-
Age-
Profession-
Education-
Ethnicity-
Religion-

Tentative topic guide:
The interview will be semi-structured the following areas will be explored. These questions will guide the interview however the direction of the interview will be respondent led.

Starting question- Can you tell me about your pregnancy?

Topics/questions to be explored potentially/depending on the flow of conversation-

Can you tell me about your childbirth?

Can you tell me about your experience in the neonatal unit
Potential prompts- How did you feel about your baby being admitted to the NICU?
Any treatment decisions you had to make?
Feelings about decision making.
Realising your baby is severely unwell.

Can you tell me a little about what you knew about NICU before this experience?
Prior knowledge of the NICU, any prior experience of visiting it?

Communication in NICU
Prompts- Who communicated the news?
Do you remember what was said?
How did that make you feel?

Do you remember your thoughts, memories in those moments?

How did you feel about the care your baby received in NICU?
Prompts- NICU care
Involvement in care of baby. Cuddling the baby/physical experience of the baby.
Support received from NICU
Presence of family
End of life care, if applicable.

Did you find anything helpful during that time?
Prompts- Spiritual/belief system?

Did you feel that it was important to have any spiritual or religious ceremony for your baby? (blessing, naming, prayer service, funeral, cremation, burial etc)

Can you tell me about any bereavement support offered from unit?
Prompts- spending time with the baby, changing/dressing the baby, memory making, funeral arrangements
Support available for your partner and family

Closing instructions-

- Ask if they wish to expand or add anything else to the discussion and thank the participant for their time.
- Explain the next steps of the study to the participant.
- Ensure participant has your contact details for any queries regarding the study.
- Complete reflexive diary/field notes.

APPENDIX 9- TENTATIVE TOPIC GUIDE- NICU STAFF

TENTATIVE TOPIC GUIDE: NICU Professionals' Experiences around newborn death

Introduction:

- *Before starting the interview, introduce yourself, explain the purpose of this research, share the information leaflet and consent form. Make sure the participant is comfortable, asking general rapport building questions*
- *Explain to the participant that there are no right or wrong answers, and the aim of this interview is to understand their experiences*
- *Explain confidentiality, use of recorder and data from the research*
- *Explain that in addition to the recording, you will be taking notes during the interview*
- *Check consent form for signature. Ask if any questions before starting the interview.*

Tentative topic guide:

The interview will be semi-structured the following areas will be explored. These questions will guide the interview however the direction of the interview will be respondent led.

- Starting question - Can you describe a typical day in the NICU

Topics/questions to be explored potentially/depending on the flow of conversation-

- Can you tell me about your experiences in providing care to newborns and families whose baby has died in the NICU?
  Prompts, if necessary
  - Role played and experiences including personal experiences if appropriate
  - The common causes, steps or procedures related to withdrawal of life sustaining treatments and challenges
  - Communication about baby's prognosis and withdrawal of LST with parents
- Can you tell me about your experience of working with parents under stress specifically with regards to such difficult decisions?
- Can you tell me if you feel prepared to handle these situations?
  - if not, what do they think is needed for their preparation
  - Any ethical or moral dilemmas

- What influences the way you provide care and support to parents?
  - Cultural/religious beliefs.

    - Prompts, if necessary- about parents' cultural/religious beliefs
- Can you please tell me what happens when a baby dies?
    - Prompts, if necessary- parent's time spent/caring for the deceased baby, arrangements for funeral
- Can you tell me about the kind of bereavement and/or follow-up support that is offered to parents?
    - Do you encourage any memory making and how?
- Can you tell me more about your relationships with parents?
    - if any bonds are developed
- Have you ever felt any impact of such experiences in your personal life or health?
    - difficulties in maintaining professional attitude
    - distress experienced
- Can you tell me about the support you receive at your work-place
    - while dealing with such situations/experiencing any distress as they would have mentioned before
    - individual or team counselling or training
- Is there anything that would change, that would help you provide better support for bereaved parents in your NICU?

<u>Closing instructions-</u>

- Ask if they wish to expand or add anything else to the discussion and thank the participant for their time.
- Explain the next steps of the study to the participant.
- Ensure participant has your contact details for any queries regarding the study.
- Complete reflexive diary/field notes.

APPENDIX 10- INTERVIEW TRANSCRIPT MARIAM

Interview- Mother

Some introduction already given to the participant. PIL and consent form shared.

Interviewer
OK, ah, so now there. Before we get on with your experiences. Just want to take down a few demographic details. I have your name. Can you confirm your age now and at the time of your bereavement?

Participant
And so I'm 34 now I think.
And whenever he's been one year, so I was 33 then yeah, yeah.

Interviewer
What is what is your profession?

Participant
Preschool teacher. Early years

Interviewer
And what was your highest education?

Participant
A levels.

Interviewer
What ethnicity?

Participant
British Pakistani.

Interviewer
And, uh, what religion do you follow?

Participant
Islam.

Interviewer
Right, OK, so just these questions. Can you tell me a little bit about your pregnancy.

Participant
And yes, it is. It's my first pregnancy I got I got pregnant quite quickly so I was trying. You want me to go in depth. Or is there any?

Interviewer
Yeah, as in depth as you want.

Participant
K and so I'm can I talk about previously or just?

Interviewer
Anything and everything.

Participant
OK so I'm I got married in November 2019 and then I got pregnant quite quickly. I got pregnant having in February or March 2020. So just a few months later and it was obviously lock down umm quite soon after. So yeah, that was my first pregnancy and it…because I've, I've also got epilepsy i so I was already on medication. So what happened was I was already on medication for that sodium valproate Epilim, but that is quite dangerous and there's a lot of problems can occur from taking that medication while pregnant and I was in on contraception and I didn't know from before hand by my epilepsy consultant that I should if I'm trying for a baby then I need to let them know in advance that they can change her medication because there's, uh, there's been a lot of problems. Like for example children to have spina bifida and Down syndrome. There's quite a lot of defects that can happen on that medication, so I wasn't always on.. contraception hadn't changed.
So the time when I conceived so I.. because I was quite scared that I'm gonna come… But I found out I was expecting I was shocked and I was scared and I knew the I knew what could could result from that medication there.. up the baby. So I waited. Silly decision by completely stopping my medications just completely stopped completely like not having morning off. And that's what few days. So then because I just thought because of…Babies just developing out. I didn't want anything to happen to the baby, so I just thought I'd do what's best for the baby without speaking to anyone. Not my partner, not my consultant nobody, and then I had a fit for the first time in many years because my fits were quite controlled by this medication because I completely just stopped just abruptly. I stop. So then I had a grandmal fit so I really..Uhm, big seizure while shaking, you know, lost consciousness. It was, uh, it was really bad on it. Haven't had for many years like I said and then obviously I went… I went to my consultant and then they found out and they change my medication and they did put me onto a lower dose of a different type medication. That's quite… It's better for the baby. And then yeah, I went to my local hospital… And in the..they kept me like they looked after me. They they were quite good. They immediately got me in touch with epilepsy nurse specialist in UM…You know maternity, so I was gained from my appointments really Happy, excited and and. That was so Lucky said we're giving me appointments with extra appointments with their epilepsy nurse and… Uh, yeah, so that will be well, we didn't have any problems and then wait for my 12 week scan everything was fine and then I can't remember properly. But I can look at my previous letters, but I know that at my 20 week scan they found umm..So they found something.
They umm they found some kind of anomalies in the scan.. the when they did this scan and data about the.. *Some disturbances* At my 20 week scan they found they did find some anomalies they you know they wanted to investigate further and then wait for you know they did amnio synthesis or they you know put a needle in my belly and I'm not include to see if there was a chance of down syndrome or some like I want Edward something. So that was a bit scary but around that time they had also found there's problem with the heart now with the baby's heart. But they also want to do more scans and they sent me to the other hospital in St Thomas Hospital to investigate further. I think I went to different hospitals.

Interviewer
hmm. Okay, then what happened?

Participant
Well see I went to different hospitals because they want to investigate it further. And I was diagnosed with different things. Well baby was diagnosed with different things. It's really confusing because first is my first pregnancy and there's so many questions as well because…First, they said it could be,

could Titrilogy, filler filler and those other those other hoppers. It was a scary time and nobody knew anything.. nothing was confirmed about the heart, the heart even nothing was confirmed so we've had heard about different.. you know, different things about his heart. Nothing was confirmed, it was just really confusing. Also because this was all happening in lock down, obviously with COVID and so my partner wasn't really allowed to come to appointments with me and with you and wait outside in the car park. But that was really hard because we did ask that, you know, can you come atleast.. 12 weeks if he could have come in, 20 week if he could have come in. Now 20 week that was the hard part, that's when obviously they found out they they had to you.. that's when obviously they said there's something concerning them and.
It will be lonely with my first pregnancy, obviously I'm not.. my mum's up there doesn't. They're not seeing anybody outside of my husband from my house and husband was in the car park so cutting in he was really lonely time and we did ask if he can come in but he wasn't really allowed but then we had another scan. After he's done he's had to never another scan again. Then he was allowed in which was which was which was good as Nice to Have that support. And then..Every day and then we were referred to Saint Thomas. Guys and Thomas Hospital and it was finally confirmed that he had a baby had pulmonary atresia with ventricular.. ventricular septal defect. Basic problem, the heart umm you know some of the arteries..you know you it was big. They didn't really explain how dangerous it could be. I did have a lot of meetings over zoom with some of the nurses and they they did take care of me in the sense that I had a lot of scans, lot of appointments, but it was difficult because I was driving to Queens Hospital tomorrow because people for normal the normal you know appointments but appointments. But then I was also traveling to Saint Thomas like up to see. For the extra appointments by the Hulk. So yeah, I had a lot of appointments and yeah.
Then we were told by.. they talked to us about how he how we'd have to look after him the way we gonna have very good, you know, when he comes home, he's going to, you know, we'd have to take care of his heart. You know we'd have to do measurements every day. You know like a heart monitor and he won't be able to do specific activities, and his life will be quite different. They are. Also, they did offer me at the beginning of the pregnancy when they found out that we can terminate pregnancy, but…I was completely against that they did advise me like it would be best for baby and for me to term labor hours completely against it, just in my own morals and also obviously islamically, we don't really do… It's not, you know, we do abortion past this specific day or..once Child's going a bit so and I I just wouldn't. I don't believe in abortion that I've worked with MSDN children. Children with you know, special needs and disabilities like Morse… Well, I've always worked in that sector so.
You know, I've seen how much support children need and I'm fine with it and I was fine to take up that responsibility as well. As long as my child in today, so I was fine. Nothing would have made me terminate. Yeah, then he was in hospital. He was born..Umm I had to be induced because the funny thing is that so is that. Three weeks earlier. I think those 36 37 weeks weeks and I had my normal appointment with my.. at the Saint Thomas Hospital and they did a scan as always and then they said to me that you're having your amniotic fluid is a bit low and they they asked me if my waters had broken and how i said… And no, I don't think so and they said, well, we think it has because you're fluid is so low and also and I was like.. I said to them that well…To be honest, like the last few days I have been quiet over in toilet, but I just thought that's normal, likely pregnant and they said no. It's not like in the movies where theres a gush of water.. how does it or I don't know like first time I've been recommend so yeah and then so they asked me to come in two days later so back to Saint Thomas again when I'm back to [Names the Level 3 Tertiary hospital] and.

Interviewer
You had been moved to [The Level 3 Tertiary hospital]? Not the local hospital?

Participant
No, they wanted. What they said is because yes, sorry about that before and they had said that they want me to give birth in [The Level 3 Tertiary hospital] just because that's more specialized hospital for heart defects and they'll get… He'll get better care there and they did advise if you want to… If you

really want to go to your local hospital or if something happens that you have to go to your local hospital then that's fine, but most likely they'll.. even if I did go to local, they'll have to take the baby straight way back ambulance to the [The Level 3 Tertiary hospital].
And obviously I ll have to make my own way to [The Level 3 Tertiary hospital], and they take her separately. So that's where the advisor is better for you to induce. Yeah, so they wanted me to induce anyway, just for the sake that I'll always be in hospital in [The Level 3 Tertiary hospital] before they induce me. So yes. So then I was there. I had to go back to [The Level 3 Tertiary hospital] and get induced. And then what happened was when I got in just the nurse, this was really upset about the nurse who tried to induce me. She had no idea about my case. I thought she had a really… I don't think she had with her case notes, but she didn't know why I was being induced. She didn't know. You know the about, the heart defect? She didn't know anything…In those.. because obviously I'm sitting there. I'm saying that there's been waiting to induce and she didn't even know anything. And then, yes, you're trying to induce me and then straight away, the machines just went crazy. It's just me and my husband. And then the machine going free.

Interviewer
She would have the file right?

Participant
You should (have) the file, but I don't know if she read it properly or not because all we know is she didn't know the reason I was getting induced. You do say she didn't know about the heart problem, so she was asking me that also why he is getting into this… She saw that I was 37 weeks. They said why he came induced him so early and I was surprised because she should have read the notes properly, but she was quite…I feel like she's maybe because she was too elderly and maybe she wasn't elderly, but I don't know. Maybe she wasn't interested. I I don't know to be honest. I was quite upset at that that you should know, especially with the heart of it. You should be aware of everything that's going on with this, you know with me, but because I've never met her before as well. You know, I've never dealt with her. She was just a general nurse I think and then yes, at the heart or a sudden the baby… she'd just induce me. I don't know, if she had done also… Don't know if she had actually done.. Yeah, she inserted the pill only, but that was meant to take time. That's what I was told beforehand. That once you get induced they even said can take up to 48 hours sometimes for you to give birth. But that's that's what we was…We was told you can be hospital for days and so straight away as soon as she put.. you know who... Straight with the heart the machine started going crazy and then the everyone rushed in like the ward consultant.. We didn't know what was going on. It was so scary. And then..his heartbeat started dropping rapidly. And they just rushed us into the into the the room, the delivery unit, and. And it was just crazy after though I mean they just said look, we have to cut you off. You have to do C-section and I was like no that wasn't part of the plan and and I wasn't ready for this. I want to have natural birth and they said…Look, there's a chance if you go natural then the baby's heart… You know there's more chance of mortality..baby is..he can be (in) more distress. He can.. hardly.. can drop even further. And then. Yes, and had to sign for the C-section and. And once he was pulled…I didn't get to see him when he was born over. He wasn't crying straight after he it was. That was scary and… They look.. at least he started crying. And then they tried to bring him because of the heart because of the heart problem. They had to take him away first to I don't know.. to help him to breathe and then after that I said, you know, I want to see him and they had… they brought him around like the back of my head to show me like from their side. But what happened is obviously I just turn my side… I couldn't get up so I didn't see him. Probably because he was in ..I don't know in this you know the unit thing, the little square thing [incubator]. So he was inside that and I didn't get to see him properly at all. And then they take him to the intensive care unit straight away and I just told my husband look you go with him because I couldn't, because I just had C-section, then yesterday.

Interviewer
Was your husband with you in the operating theatre?

Participant
My husband, yeah, actually he was allowed in there when I was getting c-section umm he was in allowed in the operating theatre as well which is really helpful. Because I don't know how I would have done it there. Yeah, then yeah, that's basically that's what happened.

Interviewer
Then they took him to the NICU?

Participant
Yeah the NICU the the PICU. He was in.. he was just swap between those two units the whole time he was here.

Interviewer
Why would he between NICU and PICU?

Participant
And I think because of just his heart, because when it got a bit better. So they moved him over to you know, to a bit more stable ward. But then he got a bit down again then we had to move him back to the previous unit, so he was in NICU for a few days and PICU then back to NICU yeah.
So sorry, it's such a blur. I can't remember parts of it, yeah?

Interviewer
No, no, of course. I understand. Just before we move forward you mentioned that during your pregnancy when you found out about his heart condition, the communication was still poor you mentioned?

Participant
Between who?

Interviewer
I mean, you said that there was some nurses who were talking to you, but they were not really communicating. There's something you mentioned that the communication was still very poor after after we you found out also that?

Participant
Yeah, umm they did do well…But thing is that because obviously it was covid, but I understand that it was a more so… Meeting was online so there was no antenatal class at all for me. I didn't take in any antenatal classes because of the covid and then there's no specific classes for me in the sense to work with, you know, to work with children with heart defects or anything like that. I I just feel like I didnt get much support. I did have support with some nurses from [The Level 3 Tertiary hospital] that would call me just to see..just let me know what will happen and I've got some emails I think as well and it was. I think one zoom class where they will talk about.. they had other parents talk about their experiences and things to expect after baby is born but I just feel like.. with that type of heart… specially it's such a lonely time and it's not a known heart defect. It's not very common at all, so I feel like I should have got a lot more support where I don't feel like I did. I still felt uninformed and lonely the whole time because… Those are the advantage of having classes, so in that sense I wasn't even ready for, you know, having a baby of.. just the child without any defects. I wasn't even ready for that as it was and then clueless like that and then also to have a child with her heart... And sorry (crying) like heart problem. I thought I was ready to deal with it, but then when I came home, I felt so lonely

like when baby was born I was a bit shocked that now what and I felt like I wasn't informed as well. I wasn't informed well even when I went into the unit to be induced. I just feel like.. I think I just felt lonely the whole time. I did want to ask too much questions. I felt really guilty for… They said, you know if there's any problems, can always call us the nurse, you know we were the whole team..the midwifes… midwife nurses but… I just felt that I would be... It's so bad like annoying them keep I don't want to keep pestering them, annoying them and I just felt.. I don't know … lonely, I guess and not supported enough, and I just don't want to be a burden on them by asking too many questions. Yeah, I do feel like there wasn't much support. During my pregnancy. I don't even know who to ask as well and who to call.

Interviewer
So.. I mean even I mean yes, some nurses were calling you, because obviously yours was a high risk…

Participant
Yeah I was.

Interviewer
Like what are the potential outcomes? What could you do… just to prepare yourself?

Participant
Yeah.. And also one thing was they didn't prepare me at all for the fact that they could be mortality risk. They didn't prepare me for that like I wish they'd have, you know, emphasizing that a lot more, because obviously it's. You know it might not happen, but there was a chance that it could happen, and I wish… I know it's scary thing to talk about and you know it's not something, but doctors are meant to be there… Doctor in this meant to be there to explain all the risks or benefits and not miss anything. The positive and negative they shouldn't. They shouldn't try to shy away from it in that sense. This should be quite open and honest because that's what you need, even though it might hurt me to hear it, but I would have needed that just to prepare me mentally and I feel like. ..That wasn't it emphasized at all, so I think that's why it came as a big shock, came over huge. It was only they would… They did tell me about there will be surgeries, and they'll be if you search (online) during their lifetime and that how to monitor him at home, but they never really spoke about…What could go wrong? Just because I accepted that you know I want to go ahead with this, you know, pregnancy just because I said no I don't want to terminate…Does it mean that. Because I mean that they should just ignore that completely ignore the fact that there could be a chance of going wrong. So there was no support in that sense by telling me that this could happen, you got to be ready, just in case. So..

Interviewer
Yeah…Uh, OK, then moving onto I mean again, you were telling me about even during your induction you felt that… Did you feel that they did something wrong or it was?

Participant
I've got so many issues with them now, that during this last week, stopping breathing because hope… [Not clear] even as.. I haven't really paid too much attention to any issues I had at the time. But now I'm starting to think about it more properly. You know, focusing a bit more, but I realize I've got so many issues the way I was treated the way I was you know the treatment I received, my baby received during that whole the pregnancy time and after pregnancy as well when he was born, then obviously while I was, you know, grieving.
Like for example, I feel.. obviously, the fact that so like I got no support. You know during.. about the heart problem and you know the grieving process of what could happen.
Then also with the nurse that being induced, the nurse had no idea about anything. You know that was very wrong for me because imagine being induced..but then they must… not knowing about the

baby heart, you know, being more careful about it. And then they will flush stained [not clear]... Nobody even told this was happening. Then what he told me my husband, what's happening. It was just all rush. Which is understandable. But it was scary because like I said, it wasn't expected. I know unexpected things happen, but again, we should be informed. But those I'm sad about that because we.. it's something sender rushed, they just need to quickly get thing done before he gets more dangerous or the baby. I did have more issue but I can't think right now. I think… when it will come back to me…[crying]

Interviewer
Yeah, whenever it does you can tell me. did you ask them afterwards or later on?
About did all these questions that you have. Why this happened? I mean after the section.

Participant
They did give us the option after it all happened…they did give us the illusion that they sent us a letter and they said and I think after as well. They did say that if there's anything you want to talk about, you know the you know what exactly happened during the surgery and things we can set an appointment, but this was quite soon, maybe 2-3 months after it happened, two months after it happened they sent us a letter. This little obviously was really warm back then and wasn't ready to hear it...
It's just hard, very odd I went on and then I just felt like. Is it too late to I do want to know what happened but. Is it too late to call in and make appointment. Will they remember the case? You know that the consultant memory? Will they be able to describe it as in detail has happened at the time. Now I've just not bothered. I just feel like it's too late and I've not really heard from them since really so I just feel like if they've given up on me, then maybe I should just give up on them like just feel like they just forgotten me. Which is fine because we were there and now we're not there so they move on. You know they are not going to remember every patient but yeah, would it be to get chance to..they did they they wrote a letter to us and explain what happened. This surgery, but it's all technical words which mean literally nothing to us. So it does say at the end… What was happening just before he passed, when they were trying resuscitate him, but it doesn't…It's just technical words. Such technical words that I don't even understand it. The format I recognize it's CPR resuscitation but. So it's either coming up to that. It's so technical that I don't understand anything. I'm not going to Google it because Google makes things worse so. I just don't really know they did explain…

But when he passed, then we went like, let's not… [they] informed us they did come and sit with us and consultant… He tried to tell us why it happened like briefly, but my mind wasn't taken it in because we've just been told that you know, our baby passed away and sorry. Yes, he said it to us know I wasn't taken ahead like. It didn't. I wasn't just listening because…I can't focus on that right now. Like what exactly happened, because obviously I was shocked that our baby passed. We like I had no idea that would happen. They told us that there was…I think they said 90% chance, 90-80 very high percent chance of the operation being a success. This operation wasn't even meant to be this the serious one. This was meant to be a keyhole. This one is usually successful. There was a bit to be…another operation would happen once he has grown.. within a year that he would have had, and that would be the more serious one. That was the more dangerous one, whereas this one there we showed us oh the consultant has done this operation many times. You know it's you know it's very common for him to do this, so you know there's not much chance of failure and it was a really high probability of the operation being a success. And I think that's where we were more shocked..

Interviewer
But it's just… uh, trying to understand from the beginning. So after he was born and he didn't cry, you said so they took him. So what happened afterwards?

Participant
So maybe he was born, you know he wasn't crying for a bit, but they took him in in the in the the same

you room you know where I was induced and they… I think they had to just give him a bit of help him to breathe and then he was fine. And then he started breathing that he just needed a bit of support and then he cried and that was fine. And then obviously we knew that they're going to take him straight away to the baby unit to help him with his heart. So we knew that I knew that from the beginning that that would happen but. ..Yeah, after he was just taken into, you know he stayed there for 11 days. He he was in the PICU, near the NICU .. because I had been induced. So the 1st 24 hours I didn't get to see him. And my husband was here with him luckily, but then after that I finally got to go over to the unit and see him. I was in a wheelchair and that was really hard because I had to rely on my husband or somebody to take me. It was really tricky because…So obviously I was in the maternity unit and I was in a wheelchair, so my husband used to have to wheel me over to the unit. And then because there's double doors there where you know it's you have to ask for entry to get in and there's another double doors to get into unit. So between those two double doors is reception. So my husband used to let me in front end in the receptionist will say well your husband not allowed to come in. He's not like to come and pass this point because of COVID and you only allowed one but that was another thing you only had one parent with the child had time, he couldn't have two children, which is fine because of COVID, but they're quite strict and that and I just want that's really unfair, because how we would… push myself in the wheelchair those wheelchairs is tricky to push yourself and just have a C-section.

Uh, he has to push me into that unit, but the reception bit and then he'd have to go out again. And then they would have to open the door and then so I have to…I have to wait for someone to come and push me to the his unit, the NICU unit. This happened a few times and then. I just felt this is just ridiculous. I can't do this that waiting for other people not being being able to see my child whenever I want to. And then I just while I stayed in the hospital as well, so they're lucky I stayed there was room for me there, so I stayed there in the unit and the maternity unit. And then because I just, I was fed up and just rely on people not being able to see who would have wanted to. So then I just made myself force myself to get out of the bed, to walk to the unit. If everyone is shocked that you just had c-section she's actually walking, but I had to do it because how else would I see my child? And he was such a such a fire. You'd have to walk quite a bit. Now we've 5-7 minutes to walk across, you know, across from the maternity unit to the… his unit was… it wasn't close yet to walk a bit, but I just made myself walked there because…I had to and then I just. I think I just forgot the pain. I was in lot of pain but I was like I need spend time with him. I need to see him. He's not even seen me yeah. So then I just send it upside to hope there by myself. Sometimes my husband went to be there to support me. there was only one day, so it which..I don't think the issue I had there, they need to do… you have four beds like 4 babies in that unit particular time. And so the baby is getting more attention and support, but half the time there were hardly other parents like one or two parents in there like me with my child…they could have easily allowed my husband to be in there with me and they didn't and so we'd have to swap. Sometimes out goes on that he would go would take shifts basically and there was only on weekends he was allowed to have both parents … because book a time and so I think there's only one weekend where we got to do you know… they got two together and you know got to see him together, which was just… It was frustrating because there was your during the days with the week days. They could have easily they just did slots again then that's not problem. They could have done slots in or even at the night hugs. My husband was around those..they could have allowed us both to be there at night when it's bit quieter…you know we wore the mask. Everything we made sure we were protected and they just didn't allow it which is really unfair because…us as a couple as a mom and dad we only got to see him to give her maybe once or maybe Saturday or Sunday. We got to spend time with him and then. Oh then obviously he passed. We never actually got to spend together time to give us a family. Also, I feel… I don't like issue... Yeah I didn't have support wise was that while he was while in the in the unit we weren't kept informed about any thing, which is something I would do, want to complain about now. I've taken more seriously. I do feel like I real…Somehow, you know, confront this and I'm going to somehow contact the hospital and relay my concerns because I do have a lot of your concerns and I'm disappointed with the service that we got when we didn't get. For example, while he was in the unit, he was there for 11 days. Yeah, so that's quite a

long time or the whole… It's not that long, but it was at the time and he when he was having the consultant was coming to see him apparently everyday every three days. But we never got a chance to speak the consultant. We don't know where he went. He went fully or scans appointments. We didn't get to meet the consultant directly so we never knew what was going on and then we would have to whenever I would go in or my husband going to spend time with my son, we we would have to ask the nurses to what's happened today was a consultant and can we see the consultant? And sometimes they say yeah if they came, we'll let you know and we'll ask if you want to meet but in never ever happy with never actually got to meet the consultant you know or any of consultants or anyone that was in charge of his, you know, care apart from nurses that were just in the unit with him. But the nurses were changing all the time, so there wasn't always just one nurse with him. The nurses were always changing, which is not met. The nurses and…(pause)

Interviewer
I mean umm, but nurses and doctors are different. So who was updating you about his condition, what was treatment?

Participant
We'd have to ask them, they wouldn't. We have to ask them. Or sometimes they come at all he's been.. He's had a good day today, but it wasn't in depth and I don't expect them to know in depth because they're not the ones that are completely in charge. It was just frustrating because we had to ask them. And we never had chance to ask about the scan that happened. You know the heart… what was the next steps, why they're increasing the medicine, why they're reducing the medicine, why they're changing him from one you know, when did he would change from and up to another unit. They were told that he's moved to know what unit because of I think he was responding well at one point, but I think then he moved to another unit, but then to a less serious unit then I think he got bit in against. They moved him back to the higher risk, you know, but we just didn't get enough support information. It was just like we weren't kept in the loop. I feel like we should have more. We should have had more meetings. You direct one to one inside a room. It's separate rooms. They can go into detail about what's going on…

Interviewer
yeah

Participant
We just didn't...

Interviewer
What… did you ask for a consultant?

Participant
Yeah consultant, can I please speak consultant? I want to know what exactly is happening. Was next door? Why how he's responding and so. But you know and then there was a scan he went for and he didn't offer and… we just wasn't told about it, there was just no communication. I feel like from their side.. so I have been addressed this for you want with it?

Interviewer
when you ask them…Uh, if you could speak to the consultant what was their response.

Participant
Yes, you let us know they don't know that when the consultant comes in, comes to the wards. It can be any time, but sometimes it's in the morning. Usually it's in the morning and if they when they do come, they will let them know that we want to speak or when they come then we'll call you to let you

know that oh he has come but…it never happened. It never happened. But obviously, just before the operation, then we got to speak to somebody so…

Interviewer
So OK, so if you can tell me a little bit about what his after he was admitted in the unit in the NICU, what was his condition like and how did they decide what treatment he needed or what operation he needed? A little bit, whatever you remember.

Pause…

Interviewer
I know you won't remember all the clinical details, of course, but just I'm just trying to understand his treatment trajectory and how would they deciding how were. How were you involved in…Uh, you know all these? Decision making factors or everything about his treatment.

Participant
We wasn't involved in his treatment. we weren't really, we were just told what's going to happen and let's understand, well, because they know best.
You know the… with his… while he was in there, so they had to because he had to use…He had apnoea, so he's just stopped breathing, so he's still have to rely on some kind of medicine to help keep him keep his helping to breathe, but also to keep the artery open to allow the blood to flow and stuff. But he was a prostate in, and because he wasn't.. He would stop breathing for bits. So he had it. It wasn't something to help him breathe. And then because of his breathing, they couldn't operate because they needed to control his breathing first. And so it was just yeah, up and down and they just told us that they didn't tell us actually when he so when they would reduce their mail processing he needed to help him with their heart when he was doing it, but they wouldn't tell us that they would do statement. We'd go in with find out all the reduced their or they've increased their.
Yeah, it wasn't.
Hey, we went who just told when we went in that OK this is happening. I wish that they'd have called us more. Just keep us updated because they knew that I was in the hospital. They knew I was staying there. Then you would come any time or my husband would come in.. They could have just called us to tell us this happening and you know in that unit they only had four babies, so it's not if there was too busy to call us. They could easily have called us or send a message like this. So much forms communication now email text your phone and even leave us just a voice you know. Voicemail, but…Yeah, just it was. It was terrible to it. Now I think back at as realize how, how much, how we weren't thinking with at all.

Interviewer
You were staying in the hospital for the whole 11 days that he was admitted?

Participant
No, unfortunately we only got to be there for maybe three or four days. Yeah 3-4 days and then they had to visit get we had to leave because I'd been there because I've, oh because my C section and my scar healed quite quickly. Luckily because I think I was also active straight away. So luckily you know I was hitting my weekly shows up and because I was talking about so they were happy with my healing, and they decided that they can discharge me from their care. So we were on the waiting list for you know, [The Level 3 Tertiary hospital]…They have their own level [Names the accommodation]. So if you heard of it about [Names the accommodation], and accommodation for parents or families you ever thought about yeah. So there was first there wasn't space for us in [Names the accommodation], and the day that we left though they were discharged wasn't space for us. I think we went do we weren't actually yet. That was the problem. So my husband Say he booked a hotel for in nearby hotel for that night. Just if that night and the next night because we didn't know where we're

going to comics if we went back to my house, which is a good may, so it's quite far thinkers and our travel Saint Thomas. And that's you can't drive really... You have to take the train.
So I hope you're going to go to hotel nearby hotel and then he booked that, but they luckily we found we just like just before we left. We found out that we had a place in [Names the accommodation].. It's much more small and not national. It's just by the hospital like a little place to stay exactly. Well it's not hotel but it's kind of like a hotel by the hospital. So lucky we got to stay there one night and then after that we didn't know what's going to happen the next night. So there was a stress that we need to make sure we give him all day or night but then also if I'm in the hospital then raise my husband going to give I'm there all day where's my husband going to go. And with my husband's in those people with him, then where am I going to go? Because there was nowhere to go in hospital, she said. Then those that worry happen.
Luckily, we found because we know where this is so perfect, but they've been up within the M25 we know, but just within the M25 my because we actually signed just within the M 25, we're not priority to get a place to stay in [Names the accommodation].. So we went. We didn't get place then because we kept asking the hospital the doctors, my epilepsy nurse. We asked everybody we had to contact my doctor to my epilepsy nurse and in nurses that were in the junior. You know, we asked everybody we could that please put refer us for they run about [Names the accommodation], because you know it will be so difficult for us to come every day to see him and we actually for.. we were told that he's going to the hospital for a few months at least. We didn't know it's just going to be a week, but we were expecting to be. I'm not saying you just want how we going to do it, especially with me having a C-section as well, or that I was working but I couldn't walk that much, only will cross the unit so I don't know how it have worked so much according to a train to bus to a train and then walked from this train station to the hospital.. it would have been just too much. So those really scared and they luckily luckily we found out that we got a place in the [Names the accommodation], so that helped because right opposite and no, it wasn't right over. It was still about 10-15 minute walk from... Still still, but that's fine as long as we are close by.
Yeah, but that was really bad because when we went there it wasn't even full capacity at all. It was so empty that one looked on that thing that got four floors. They got very large buildings, got those four floors and lots of room. It's like it's the size of a hotel, it's it's a really big, a spacious. Everyone at the house was actually really good to us. They gave us a lot of support. They made sure there was food available. It has a big kitchen food available if you know you can't, you don't have the time to go out and buy something to eat. You know they were really good. But yeah, that was really stressful because we didn't have anywhere to stay. And just because of the fact that we're within the M25 we are not priority. So that was really unfair. No, no, that was really unfair because they given priority to people it shouldn't be according to where you live.
But it's basically the fact that the place wasn't even busy. I thought it wasn't empty, but I spoke to receptionist. They said no, we did not full capacity at all and they got a lot of spaces. So that's where we would just be surprised about that. They could have easily have given us space, but I don't know. I just feel like the doctors, nobody was pushing it, we weren't priority for them. They weren't worried about the parents.. where parents going to stay what parents going to do. Yes, we were just wasn't supported in that sense by the. I don't think I even met the consultant until the surgery, and I don't even know if he was consultant who was in charge of the care.

Interviewer
So then what happened when? He was in the unit. I mean, you've told me a little bit about your experience…can you…

Participant
So when he was in the unit. They were keeping an eye on his stats then. They would give him medicine to keep the UM, the artery open that then. Few days before prior to his surgery his operation, I did say to him look and you know you can operate, like you know why you… if he… you… kind of… [not able to form sentence], why you know they said that they it's not…You know they don't need to

pray. Yeah, we know, we have to wait for him to grow, but he had started growing because…. you are producing milk. So then that would help him to grow as well and he's got he's growing a bit more which is good but they didn't want to take him into theatre.. Suddenly not… Then monday they must have taken for scan, and they said they were going to OK, we're going to… It's starting to.. starting to... They had a bit of concern about his arteries. They had decided they are going to operate like the next day. So then.. I was a bit surprised why you waiting till the next day when you found it on the day.. Why couldn't just do it on the day, but that's fine. So the next day… then he went in for surgery because they found that his arteries are closing they needed needed to keep it open. They wanted, but they wanted to put the stunt in to keep the artery open so that the blood is flowing. He'll be able to breathe and…Then they yeah they took him in and I think..doing the surgery at last thing we don't even know like… If they wouldn't put stunt in just to keep it open the artery open. That's it, but. We didn't. We don't know what happened during the surgery. If they put this thing in or and then yeah he passed away or they hadn't managed with stunt in. I don't know. I actually don't know what happened during that operation. Well, they did tell me that with it they they we tried to resuscitate for a long time but…umm At least they tried any more than he would have been brain damaged so yeah.

Interviewer
So who, how long was the surgery for this?

Participant
It was meant to take a few hours, they said because they have to prepare him and then are... Then they have to do surgery and they said it be a few hours. They told us to go out. We left the hospital. We just walked around because… Yeah, we just thought it's going to take hours so we need to keep ourselves busy. And they called us within within an hour, I think after an hour they called us yeah and we were quite surprised because it wasn't, you know, it wasn't meant to be that quick and…

Interviewer
Who was it that called you?

Participant
Someone from the hospital. I don't know if it was the consultant must be even the nurses not the consultant. I think it's a nurse because she called us and she said…Can you please come to the hospital? And then we had a really bad feeling and then...I ask what is it? Is it bad news? And then they said, well, it's not good news. You need to come. So even though I tried to run but yeah.

Interviewer
And then then what happened? Who did you meet?

Participant
Nothing.. it’s a blur I remember going in the hospital and faster when you.. like this man nurse or somebody at the front he wouldn’t even let us in. Both in because yeah, that was terrible. That was really bad. We went into [Names the unit]. This. That's where it was, the operation he went in and I did. It was the nurses who called. Somebody wouldn't let us in because we didn't have appointment. We didn't have a file anything and yet here he was trying to call. We said look look they told us to come hurry up. We were getting frustrated and the guy said Oh no. But you know if you had some file.. I said look when husband just ..like we need to go like and then..He's tried to call the guys trying to call somebody upstairs.. somebody from upstairs came downstairs to say no yeah, you are allowed and it was just ridiculous because, ah, even they should have been warned or something. That was really bad and then here we ran up and then we got taken into a room. Nurse came in to calm us down.. started just to this..You know he's..something happened during the surgery and then and they just told us that…

Interviewer
It was a nurse who told you?

Participant
Somebody from inside the… I think was a nurse or something Dr that was inside the surgery in that was involved in. I think the surgery. It wasn't a general nurse. I think there's a lot of Dr that was involved in the operation. I think I think I don't know, but yeah, she just… She told us that you know in this happened and then we were just unsure? I think my husband was very upset straight away, but I think I was in denial or shocked because I didn't even respond. Now look I I'm just shocked because they told him later this is what's happened. I didn't respond. I was just in denial that no nothing going wrong like I just I didn't show any emotions. So I'll… but I just didn't believe it. I just didn't believe it wasn't possible to me like it didnt it make sense? And only after about …Yeah, it's realized, but yes, in the hospital, think the consultant guy that was in charge. I don't know. That's something I don't know who I don't know who these people were because it was just such a blur. I think he was the guy that did the surgery though he came in and spoke to us and told us what happened there. It didn't mean anything to me at the time because… those were just words like I didn't didn't mean anything, and it's all rushed. Everything happened so fast…Then afterwards they brought the baby in and I was still in shock. I just leave sleeping and yeah I just want to sleep sorry.I just wanna see if I didn't and it still didn't believe it and then.
I'm think I was on the phone and they must have called my mum or something and then they talked to my mom. I think their nursing there was nurses in the lady nurses. And they kept telling me look your baby's dead like you know he's not here. They they tried rubbing it in me but I still I didn't. I don't know, I just didn't believe it sorry. They spoke to my mother said look they couldn't get the sight right. What they're going to take me in for psychologist. They get psychiatrists, yeah,, psychiatrists because I'm not responding properly or I don't know why they said to my mom that look here to talk to because we figured you get the psychiatrists because she just not believing it should. Just they thought I had gone mad because I wasn't crying and I was just like I think he's alive and… I didn't know how to react to something like that, so there because of a reaction they said to my mum that look she got a call.. Uh, we going to call psychiatrist on her. Basically I think my mom had to lash out. She said, ..yeah, you need to get a grip basically, but then.. I just didn't expect it like it wasn't meant to happen. They didn't warn us, it wasn't... It wasn't even an option.. it wasn't meant to have had. Then after that I did get a… They let us stay there. I think we stayed that night in? …about dawn and then we left the next day but like after we got a… we got like a letter and explaining what has happened and they did invite us to come if we want to talk about. But at the time it was just fresh. Don't want to.

Interviewer
Did the psychologist or any any counselor come and speak to you?

Participant
No, psychiatrist didn’t come..
NNo..

Interviewer
No one spoke to you?

Participant
In the hospital.

Interviewer
Yeah?

Participant
Yeah, we had the…Yeah, I have the that we had that that I think is a consultant. He told us what happened but that was sort of the day those too fresh like I wasn't really taking it... There's just still be shock.

Interviewer
Did you spend some time with your baby?

Participant
Yeah, yeah, we could spend some time with him.

Interviewer
Uh, and was someone there with you at that time?

Participant
Yeah, it was two nurses two lady nurses. So I think they were doctors. I don't… I think one was a nurse…these people I don't know who was who. I really do.. After I got back, I was at my lowest, we had a bereavement counsellor come to my house, but maybe that was for two weeks after and I don't know. I think she was probably sent from my local hospital. Yeah, I think she said local hospital before she wasn't sent from [Names the Hospital]…
And when she came to keep up, and she came for two weeks, she came twice, but I just felt like she wasn't taking me seriously enough. I felt like I didn't need her because she was.
She was.. the way she pushed.. her approach wasn't really comfortable with me. For example, she she kept giving examples of other people who heard stories of other people and. She's bit too jolly.. I guess like so please just stop… needs… and she's keeping telling like his output, so she went to this person and that happened. I don't really care to be honest. There's not that time and then she would say things like you're not depressed, you're just sad. And that really affected me because I don't want to hear that I'm not depressed. I'm just sad that because that means we feel even worse. Well at home, maybe for worse that. So I'm not having the right emotions. I'd rather have been told you're depressed rather than just sad.. Sad just doesn't seem like a strong enough emotion, if that makes sense. [tone- anger, refer fieldnotes].. That's when I just decided I don't want to see her anymore and I just when she messaged again to make another appointment and I said no, I think that's I don't need at the moment. Thank you. But and then after that I haven't really had any... Well, the doctor did. My local doctors did offer counselling and I said yes to it, but… I haven't received calls info, nobody contacted me and that's been a year, but I haven't received any counselling, even though they offered it to me. I don't know if I'm in waiting this. I don't know what's going on. I haven't heard anything, so that's a sad thing that…Like as a mom that went through like COVID, so basic COVID was, you know, my baby was born during COVID I was completely alone so I couldn't have any family come visit.. my family didn't get to see him, nor was my family was able to support me. Obviously you past it now… I had the toughest time ever and when they even offered me counselling that proper counseling and I said yes to it. I didn't get it and it's been a year and I still haven't heard anything and you.

Interviewer
This was after you said no to this bereavement nurse?

Participant
Yeah, the bereavement nurse was sent from the hospital. But then the doctor after while the doctor called me early, and spoke because he found out what happened and then he asked me if you want to get more counselling. So I said, OK, yeah, because I thought maybe I'm ready for it then. Then I haven't had means and that was thinking. There's been a year and. I just feel like during that time I could have committed suicide. That's the truth because I had so much suicidal thoughts since and… Nobody to talk too like my husband and I don't really talk to my family because I don't upset them... I

don't know like sometimes you don't talk to your friends because your family because they know you don't want them to feel negative. I don't make them feel always sad all the time, every time, every time they took him to be. Then I'm just crying. I'm just sad or just, you know, in a sad mood. I don't want to take that low energy to them. I have also sometimes I don't talk to them here. If it's someone from outside.. Nice talk to somebody outside.
I've had so much since.. I don't fault, and luckily because of, I think the only reason I haven't done anything silly is because of the fact that I'm of my religion, because obviously my religion.. Like if you commit suicide, you go straight to hell. That's the only reason I think I would add because my husband is, well, my husband has been through a lot so he lost his mum when he was young, at 13 when he lost his mother to…She had a sudden brain haemorrhage and passed away so he lost his mum quite young and then he lost his first child. So he's been through a lot as well. So I thought if I go like I don't want to do that to him. So that's the only thing that kept me going and just my faith like just praying, praying, praying that's helped me but I've had no support from like doctors or any system and any like agency and who organisations afterwards.

Interviewer
Did you try reaching out to any of you know.., Like how Sands there are some groups as well?

Participant
I don't know how to like. Uh, it's there,, I don't know how to approach them, and it's just. I don't want to say to them like oh I don't. I don't know if it's hard to describe.

Interviewer
Well, I mean you have to describe the way you've described it to me…Nothing. We'll. We'll discuss that and I will ..I can connect you to someone from SANDS? I think it'll be good because… Yeah, I mean it's good that you found solace or some peace in religion. That's good, but I will if you…

Participant
I've had support from my family friends like messaging and stuff. They wanted to come see me, but yeah, it's that's good though. Got good support system in terms of my friends or family.

Interviewer
Yeah, what do you feel.. How do you feel about the care your baby received in there? Nice you, you've told me about the support you had, but.

Participant
I don't know because I wasn't there all the time. I don't know, but I think he I think he probably did get good care because I know there's always nurses in there and there's only four babies in within one unit, which was really good because that means they get extra…You know they get extra attention, so I do, you know, I don't. I don't know. I don't think he got big in that sense. I don’t know..

Interviewer
But while he was admitted in that time, did you get to spend much time?

Participant
Yeah, I did get to hold him when I was.. at 24 hours later when I've got to go and see him I held him. But yeah, that was another thing that I found really sad. The fact that yeah this is, I one, complaint. I do have his. He didn't get to bond with me on and get to work with him because. I know that when people have a C-section, I've known people that have c sections and they still got to have the… You know the baby’s first touch. You know it wasn't a question. Yes, skin to skin. I didn't get that which was really sad because they could have done it even for a few seconds, but they didn't. Or even after getting settled they could have brought him to me and they didn't.

Interviewer
Skin to skin?

Participant
Yeah.
I think that I think that did affect us both. You know, we had him at there, yeah, but if I did go to the unit, it was hard to hold him because I'd have to ask the nurses to give him to me because he'd be attached to wires. And then sometimes I just feel so bad to keep asking in that oh..Can you take him out because there's so many wires? So if they could move around too..So a lot of time i was just standing over his cot and just touching his face anything because I was too… I didn't want to keep asking them because I thought I was annoying that every time I'd come and they have to move the wires and it was hard work. I couldn't take him out myself and need support… because they would have to do it so I didn't even get to hold him as much as I would have liked.

Interviewer
You know you've said this a lot even when you were telling me or pregnancy… Uh, your birth experience and afterwards that you didn't want to ask them? You didn't. You didn't want to burden them. You didn't want to ask questions. Why do you think you felt like that? Why do you think you were feeling like this?

Participant
Just because I don't.. I feel guilty, I feel badly asked them to go out of their way and they seem so busy like the most they felt it seem like they were so busy doing other things I don't want to keep asking them. I felt guilty for making them do extra work if that makes sense, like…It's just a bit. Embarrassing this feels a bit like a burden on them and we could see… they obviously busy with their paperwork on their computer, and I don't know with other babies so I just didn't want to give them extra Headache or…

Interviewer
Do you think your husband also felt like this, or was it only you?

Participant
Yeah. So I know he did feel like that's where he didn't. He he's being more stronger than me, so he was able to ask questions him. But sometimes he had that as well where he didn't want to keep asking them. Because they weren't really…Couldn't score string on as they would just go straight. Others as well, like over babies and stuff. But I do feel like if we were only within there they would be more attentive. And more understanding of apparently. Obviously I know some parents you know, nurses, they do shift work and you know they do nights, so they did days and they're tired, but you're there for the child, but also their parents and their family. I feel if we got more support, care and just they need to understand that. It it's not just the baby, it's his family, his parents, you know. There's some kind of love and affection between those that family like you need to provide, that that's why you're there for, you not just there for the admin work. Now I know that nurses are overstretched and things but… You knew that was the profession that you know there's part profession once you studied for it.

Interviewer
Yeah, right. And OK, so you you did you? Can you tell me…Were you given any bereavement support while you were in the unit after? I mean when you had the baby like you know, there's they do things like memory making…

Participant
Yeah.. So when we come, I have read we obviously, but he passed away and things everybody came

through then. And they showed us that there was a little memory box that.. they cut a piece of his hair, gave put in the box and. They did… had his handprint footprint that could deliver to us, so they were quite good with that. But uh, yeah, they did those things.

Interviewer
Did you take any photos with him?

Participant
I took photo photos with him on my phone while he was a… Yeah, while he was alive.

Interviewer
Or as part of the memory making they took any photos?

Participant
No, they don't.. me and him? no, but he was passed away so they won't take pictures of when he passed away.. no they wouldn't..but not during his life no. They didn't take any pictures.

Interviewer
OK, do you think that's something that helped you.. is that something that you found helpful?

Participant
The the memory books are to be honest, I don't really look at it still because my husband likes it. My husband likes it completed, but I find it to difficult whenever I see any of these things I get really like really upset. Like uncontrollable. So upset, so I'm hardly look at you. Sometimes you know, you see the hair so it's nice to see. I'm glad they did give us that.

Interviewer
Sorry, I'm just going back again to your pregnancy period, but there's one thing I want to ask you, like of course nobody…You told me that nobody really prepared you for what could have been the potential outcomes. But you knew that he was going to be taken to the NICU. Did you have an idea about what does it? What does like what to expect from the NICU? Or did they?

Participant
No.. Yeah, I didn't know. I didn't know what's going to happen while he's in the NICU PICU. I didn't know what they're going to do him it's I don't know what happens in there. I didn't know the difference between NICU PICU like. You know all of this was brand new to me and nothing was explained. All I just.. did know that when he's born they're going to have to take him into the unit just to help regulate his breathing, because obviously won't be relying on me anymore. I didn't know about, I didn't really know about what's going to happen after, so it was also new as well confusing. So all these different changes every day going in hearings. This has changed that's changed and asking them why haven't we been told. I haven't really informed everyday something had changed which is going to.. we wanted to know. We were glad he's changing but normally for… because we would have to ask and that was frustrating because. Why do we have to ask? Then they would tell us such? Technical words because it's rush because we've asked they say, Oh yeah, routine this. We've done that, but it's not in depth because, well, then, how are they.. nurses are not going to know it in-depth.. other reasons.. No one explain it properly. They just assume that we know everything. How can Anyone know anything.. Yeah, I didn't know it's going to happen after he was born and…I didn't, I didn't… We didn't know about if he's going to go into NICU PICU we didn't know and… They did tell us about this surgery that he's going to have certainly did explain to us before surgery. What happens, but I wish they'd given us more information sooner. So it wasn't just on the day. because other day you just say yes we did. Yeah go ahead with it. You know whatever you have to do to help him. And they need to understand that you know it you use these technical words, but as with his doctor. But if we just we not talked as

we not qualified in that kind of we don't know what this stuff means. So they should really help us make sure we understand everything, put it in to words you know, put into words that we understand that we can comprehend. I feel like a lot they could have changed.

Interviewer
Did you? I mean, did you get to speak with any other parents if they were experiencing similar things or?

Participant
So I experience some you know some parents views and stories. When I had that one, I had one as zoom meeting and that was 50 hospitals and she set up a meeting like that with other parents that you know, I've been very similar so it was similar heart defects so… that was okay

Interviewer
This was after he passed?

Participant
No, that was before. Yeah, that was what maybe for that was my last pregnant….

Interviewer
You've told me that in afterwards religion has been something which is which in which you found support. But while you were going through this period… What was it that you… How What was it that was helping you or?

Participant
I'm sorry which period.

Interviewer
NICU period. I mean after what you've told me when you were grieving that you know religion has been very helpful and of course what your partner had been through.

Participant
Yep.

Interviewer
But during that period while you were going through all of these, you know you were living through that…

Participant
So while I was on my.. after you mean after I'd given birth between becoming very birth and passing? I'm sorry, what was the question.

Interviewer
Was there something that you found helpful during this time? Or what was it?
I don't know how to ask now.
Uh, like for instance…What do you think? In that time you found or you sought support in or you found it helpful that kept you going?

Participant
Just like I said, just praying and that's one thing really kept me going.
It was difficult because at the time I wasn't able to see family or friends known as allowed to come to the hospital, so. And that was difficult, but I think I didn't really find peace at all because I was so

stressed about him and every still guilty if I left him. If I wasn't with him like I'd feel so guilty when I would go back to the hotel back to the room to sleep in, but I would feel so guilty really give me for not being with him that 24/7. Yeah, I think I didn't really find peace in anything. To be honest, we just used to pray by his bedside.. Nothing really was comforting, you know? We speak to the nurse is like they update you and yours is updates and they tell you what's happened, but that's not comforting. it was nice when obviously they tell you that he's done well. That was really good to hear…. I don't think there was anything I found Peace in.

Interviewer
NICU times are stressful for parents….

Participant
Yeah.

Interviewer
And umm, how did you then? I mean, arranging the funeral and everything. Did you have support from your…? Because it was COVID time, wasn't it?

Participant
And while then obviously people in the hospital and last day in the.. Uh, you know when we found out what happened, the end of in the room the uh. They got they..luckily they got a a Imam like a Islamic priest to come and say a few words like prayer. So we prayed and said a few words which was nice. Took a while because he said to call him so I think within an hour or so he came and then came the room and just like praying something and give it a bit of words which was nice and he after daring me to come home we did take him home my the next day so we had to leave. That was really that was really hard. Because we had to go home and he had to stay in the hospital because they had to put him.. I don't know where they put him..I didn't know where they really put him, but yeah, so that was really hard. That was really difficult to leave him.
Yeah, I I'm sorry. (crying)

Interviewer
Don't worry, please you have some water.

Paused.

Participant
Yeah, sorry about that.. When we got home.. then the next day my, my brother and I think they had to get something signed. They oh that was a rush around thing. Luckily I didn't have to do anything. I'm lucky that you know my husband, my my brother and brother-in-law. You know they're really helpful, so my sister they had to go and get I think get that outside from the paper signed for the... I don't know what to get him released basically and then. I actually before that… I think was it that morning we had to go and get him registered. We had to go to the registry office. Me and my husband had to go to registry office and get him…His birth registered, but at the same time his death registered, which is really difficult because your registry go back to different methods same time. So that was really hard. And obviously we have to do it because then so they will release him so we can bury him. So then….. Yeah, I feel like we got that and then my brother had to go and pick up my son from the hospital.. and then get to our prayers and stuff and then make sure he was buried by that day before.. it was all rushed to..make sure he's buried by specific time before we even got delayed and they need to wait till the next thing you... I wanted to wait till the next day. I wanted to wait till the next day. I wanted as much time with them as possible at home but they said you can't do that. Can't just keep him at home like it's not right and need to bury him straight away and it's not good for you either. To just keep it like that and it yeah, so we have to break up right? So I don't I don't really get much time

with him even because the time was going so so quickly because they went to pick him up. They got here from those with their comeback I just got maybe or I don't even know how long we've got… less time with him. I'm just saying because it had quickly come to the burial at the, you know, because he they had a slow at the graveyard to bury him. So it was just so rushed and…I had my family but also because of the whole covid looked at couldn't have too much family of route and. Yeah so…Had to be so careful.

Interviewer
Did you get to change him? Do those kind of things?

Participant
What he was born? When he was alive?

Interviewer
No, after he passed.

Participant
Change it, would you mean by changing?

Interviewer
Like some parents, like when you know when you're spending that time after the baby's passed. Uhm, you get to change him.. Change the baby, clean the baby, put him or her in new clothes... Those kind of things.

Participant
Yeah, I think I did because that's when they brought him to me in the hospital. Then they asked me join to help change his nappy I think so. I think I did help a bit but then it got too much so I was like OK I can't do anymore.

Interviewer
And then at home before he was taken away for the burial…

Participant
Yeah, go to hold him there. We didn't change because I think my brothers did it. They have to put him in a white clothes. Yeah, I got to hold him.
Yeah, they they just didn't give him to me for too long because I wasn't. I wasn't giving him back. I wasn't letting go so they had to kind of...

Interviewer
Yeah, it's been very hard, isn't it? I I think I have more or less everything. I will check once… [Pause] Yeah, I do have. Is there anything else that you want to share with me? Anything at all is fine.

Participant
I have completely forgotten now. Yeah, I do have a few issues that I would do what I raised with him, though I think I will, but I just don't know who to contact you know I don't think they did. Was they took away my my notes. You know my husband. I just wonder why they did that because… So I'm going to ask if I could have access to it again because I've had.. only they keep your notes after you give birth, but it would be nice if we need to keep it just so that. I don't know, just some comfort to read about what he's will happen at each point,
I am going to ask that if I can have that.
Yeah, I just feel like…Even without COVID, there's always just because it was COVID locked down. That's not the only fault here. There was no communication.. they could have done by zoom or so.

Any questions I feel like I didn't have no support. They could have done in his operation sooner. They did. They took. Everybody took too long to do it. They were messing around with his medicine for far too long and it's still like that was quite wrong. And don't really treat him as well as they could have. Yeah, I just I don't know. I don't feel like they've... not neglected him but I don't think he got the care that they should have given that attention they should have given to him.

Interviewer
You didn't raise any questions afterwards?

Participant
No, the time no because it was so… If it's happened so quickly and then we had to leave so quickly from the hospital, didn't we? We had to leave the next day, didn't talk to anybody, and then have it really obvious had that letter to ask it for you. Want to talk about? Everything, but then we didn't go. Now it's feel like it's too late.

Interviewer
It's never too late..

Participant
Yeah, why did they will give you answers anymore? Because it's been a year. I think that's the thing with these hospitals and this kind of care that. You'll never get, we don't. We don't get the kind of care that.. obviously we are lucky that NHS is so good. It's free and it'll be quite lucky in this country. But also caring doesn't come for free. And you need to take into account the parents and keeping them in the loop and explaining things and just plain English, because we deserve to know what's going on, the changes they're making why… There was a few of his uh, which I mentioned.. I wish I wrote it down now, but if it does come out to be like, you know. Yeah, overall I'm not happy with the care that me or my son received I am not… I just want to. They should have even kept a more eye on me.. obviously I've got epilepsy as well. This is not just hospital to be honest. I think it's the NHS in general.. the doctors as well. Their doctors haven't even checked up on me.. you know I had to cut.. Obviously I spoke to my epilepsy consultant and you know he's been around for my health and what happened, but I just know they don't really…there's not much about aftercare.
Issue with people that have children… Either they did say actually don't have to admit. (audio not clear). They did say that next time I get pregnant. If I get pregnant then they'll give me extra support. They will give you extra care. Because obviously I've had a childhood grief so they could give you extra bits in the beginning, there wouldn't be extra scans and there will be, I think a bereavement nurse like with me from the beginning, but I don't know how much of that is true and hopes that they will actually happen. But they did say that that next time if we get pregnant came from they would have somebody there from the beginning to support us.

Interviewer
Did they tell you why he developed the heart condition? Did you get?

Participant
No.. they didn't say just said that it's just one of those things that happens is not living if you did, because I did think, was it because of my epilepsy medication? But they said no no. It's nothing to do with that. It just happens. Some people just rare case. They said it was quite a rare form of heart defect as well so that… Yeah, they said it wasn't with my eplipesy…Anything, so that was a relief..

Interviewer
yeah..

Anything else that you want to? I mean, even if you're not able to remember right now, if there are things that you want to share later on, we can always meet again. You know, for 5-10 minutes, whenever you feel that oh, these are points that you think are important, but you've missed.

Participant
Yeah, I'll just try to give me a second.

Interviewer
It's, uh, don't put pressure on yourself. I will be in touch anyway. I mean I don't want you to feel like this, is over.

Participant
Yeah, but I know that your folks who like culture like as well I think. Uh, parents. I did notice that, for example, is obviously I'm I'm privileged, I guess to be able to speak and understand English fairly, but find that there was one parent who I felt really bad for this one lady. Next to me, feature Somalian social wishes from another culture and her, she said, Mama she was having his first child and she was in the unit but she had no English was really very limited English but she was… She was from this generation where they didn't really learn or go to schools. They shouldn't quite older than me. Maybe their fifties, 60s and 50s. I think, uh, we were late 40s, but there she was really struggling to communicate with the the nurses. She really struggled proofing. With it that I was turned off so hard to see because she she's trying to like use a hand that had just just with the nurses. But I think I'm guessing that her husband probably swamped at English, but because she was only allowed to be there alone, she really struggled like I would see her. You know, in tears and I just got so sad for that. She's completely alone and she cant even know what's going on with the old child. That was really sad to see her like that. But yeah, I feel like they would not support for people with from other. If Misty's nuts in like people that speak different language that might have an English as a language barrier like we have language barriers and stuff. So yeah.

Interviewer
No, that's a very important point. Yeah, thank you for sharing that.
That is very important, and yeah it is. I mean. Unfortunately, I'm also able to interview only those people who are able to speak in English, but that is a problem.

Participant
The culture that we come from. Not just Asians, but maybe it's not a Muslim, but he's just the… I also use it even just in Muslim or Pakistani culture. I think it's just ethnicities in general, like for example from Africa, Asia. I think there's just this thing where we don't really… We don't talk about if there's anything like special needs or anything we don't really talk about it, and because it's a bit of a new thing. It's scary, you know, no one knows people don't know what support it is out there as it is like special people that are not educated here. They don't really ask questions they don't know what support is out.
And also a bit ashamed as well. There's still that shame that people sometimes get stupid to find the child got, you know extra needs or illness. They don't want people to know. And I guess they try to ignore it. But it's not just them. I feel like that NHS is very much cultural now. They've got so many people, workers or people that work there from different cultures. If it's this easy, they should foster, more include diversity in their training and give me support for people with you, know for parents or families from different cultures of disease. And you know, maybe explain things to them in a bit easier way. Give them extra support knowing that there from a culture that is a bit different.

Interviewer
That's a very important point.

Participant
Feel like maybe with me, for example there or my English is good and I was educated here and everything, but Even so I'm still from a… I'm not from a white, you know, middle class like obviously I'm from a different background. Can there be more support, not more? More informed about my child.. I'm not entitled to more support, but just different types of...A more informed about my child and the reasons why these things are happening, you know or support like him given? It's quite an understanding because I feel like there's no that's support understanding things maybe. I don't… I don't know what I'm saying to be honest I don't know.

Interviewer
I understood completely. Yeah, what do you think?

Participant
Still taboo subjects. This kind of thing is still quite taboo in our community, so. And like I don't know out there that like for example, you said Sands. This is, I think this is a major thing. That means be considered is. Yeah there is Sands and I've got I've only you know I've only found out that Sands with Facebook and just through random Instagram scrolling in these random topics come up. So I that's how I'm saw tommies and SANDs. But I wasn't really told about them from the hospital or anybody like nobody told whether it's only because I was doing random scrolling liking random posts ..

Interviewer
Is that? Do you think this?

Participant
reading and then these you know if you like something you go for it, then the algorithm other things come up. So then that's the only thing I came across 20 years and then SANDs. But I wasn't told about anything. I feel like that's one thing that our community is... You know these are things completely lacking support after bereavement after her grieving and there's nothing there is no supply or nobody talks about death, nobody talks about grieving and I I feel like I didn't get no support. For example me. OK they would count so I could go for counselling yeah, but the counselling, I'm still waiting this I think I haven't been in vain updated about what's going on and like I said I could have quit so he said if it wasn't for my religion and I'm sure you fully commit suicide if they don't have faith because it's a really difficult time. It's a lonely time. You're going through the worst time in your life. Ever and you got no one to turn too. And sometimes I'm sure it's other people from my community who probably feel like they can't talk to their husband because not everyone's husband is understanding is like.. I'm lucky. I'm just lucky that my husband's a bit more understanding like he will listen to me, but not every husband like that, so I'm sure there's women out there, specially after we even… Women don't really share with their husband. They don't feel because husband, men are in general, they're quite… They don't express themselves and don't want to hear anything else saying I've are so these women must feel so alone and they would not talk to him. It's hard and that's what drives people to doing difficult things because and that's what drives depression. I think depression is so so linked to I think depression is definitely linked to the NHS not giving the support that we need.. People, you know, bereaved parents need... There's a ,if there was a research done, you would notice that this a huge link between depression and in in our communities in ethnic communities. Because we don't get to talk to husbands and your parents, you know you don't want to upset them with me. I didn't speak to my mum even now. I tried to not speak to my mom about it. Sorry am I talking too much.

Interviewer
No no, no. Not at all.

Participant
And I don't really speak to my mom or my dad about it because I feel like I'm going to upset my mum won't upset even more because that was her first grandchild so. I don't want to make it quite more, so I tried to, you know not to pay too much my mom because if I crawled up she's going to cry so I don't talk to my mum about him much and I'm lucky I got my brother and sister so they're really supportive you so they'll call me. They will check up on me and things but I don't talk to my friends, my cousins, my process too much about it because I feel really bad. Like again the same thing. I feel guilty for putting a burden on them, making them feel sad and low and I just feel like it's been a year. I shouldn't be sad anymore like they're going to think, oh, she's so boring. She's always depressed and talking sad or crying. So I tried to stay away from them as well… My friends and family… I don't go out too much because I don't want to be the one that you're the downer.. who brings it down out to everything. So if I had… Yeah, last thing we've argument we don't you know Asian African people. They don't know that there is a pull out and with me like because I don't. I didn't turn to like you know SANDs, where you can ask for help… Just talk to someone because.. I wonder why we just we don't because we won't turn to someone because he's an outsider or they could not, going to give us the… Umm, going to give us the.. Well, maybe the support we want not even need support we want... Let's put me one because sometimes you don't want to hear that… Like for example with me When I was told that. Oh sometimes they say, oh God I will give you enough. You have another one. Or you know. You should…

Interviewer
Who who said this?

Participant
Like I think we've uh, if we get that from your friends, for example, that all you or your family that you have a normal, it's not something that you want to hear but I don't know why we don't turn to... So I I feel like I think maybe it's a I know this is not racist thing got anything it's just I'm trying to think of the reasons why I didn't because. The reason I did it's probably maybe the reasons why other woman from .., but we've I think maybe the reason I don't really turn to SANDs and Tommy's, even though I know they probably will go support, I don't know the type support they will give give..support they provide and also I feel like if I did, if there's somebody there like accounts or somebody that talks to you, they're probably not understanding me because I'm guessing I've just assuming that they're probably why middle class people. That don't understand me my situation.
And my circumstance sees my background. I don't know. I'm not from a rich area at all. You know, I'm not. I'm not working at the moment I'm, you know, I'm just. I guess working class I'd say so if my area is not some affluent area. Yeah, my image that I'm from like a general like east London I am from East London. So as you can imagine he said there's not much support out there anyway. We're not very… We're very different to the upper class people so.. Yeah, that's why I wouldn't turn to Tommy's because they just… I'm guessing that all they do is call you and listen to. You know you have to call them. This is what I'm assuming that they'll call. You know you'll call them sorry, and then they'll just ask you how are you? How are you feeling? OK, and they just want you to talk because I'm home. You want to talk, but sometimes you want them to tell you something. That's what I think I would expect from counsellor or someone to… Kind of dissect what I'm saying and then.
I don't even know what I want from counselling, but not for them to be like oh OK, yeah, so it feels patronizing in a way. That's what I don't want. Think that's what that's why? I probably don't. I wouldn't contact SANDs or Tommy's just because I don't know what to expect from them, but I'm guessing won't be the support I need.

Interviewer
You know that until you try, isn't it?

Participant
But I know that's the reason why I know for a fact that and people wouldn't like, specially from Asian communities and I'm I'm… I'm pretty sure from like black communities as well is like that. Because when you turned it out, you just seems like they're just a fund raising, fund raising and what support can they really give? Maybe? Or maybe maybe. I wouldn't call these help lines.

Interviewer
Yeah.

Participant
But I think maybe what would what would help. I think for me what could have helped me if there was like classes near me or… I don't know, I I don't know myself what would help. But maybe yeah, just face to face. But I think what really put me off is when the lady said to me that you're not depressed. You're sad, you're just sad. And that was really. That was like demoral…I demoralising. That was just… It just felt so patronising and just putting my feelings down as if it doesn't matter like… that just it's I think with counselling its really important what you say.. what to say what not to say what would help because yeah, maybe I wasn't depressed but that's not what I needed to hear so soon.

Interviewer
Yeah, you're right.

Participant
But do you agree? Or do you think that I'm more about should be done with people from, you know? If this is, they need to get more support and help and the things that you know people do research, but…People are not willing to do, he says, because they don't know that… research is out there? For example, if I hadn't seen your Facebook, was it your Facebook? I saw a post from if I hadn't seen that then I would not have known about this stuff. And that's the thing that even though you do say it, I'm not saying anything bad about against you. But I'm just saying that… And you say there's not much participants willing, but how much have you, you know? Like how far is your network being for example like how many people have you actually asked? Because there might be people out there willing to talk to you. Maybe they'd prefer face to face or maybe over the phone. Umm I mean, maybe for email they are different ways or speak to it. Maybe people just don't know, speak or for maybe people rather stay anonymous, but you need to not just you, but all these researchers they need to if they want a wide range of you know people, different ethnicities, different genders than they need to cast a wider net. That's what I think, because like I said, if I hadn't seen your post then I wouldn't be doing this right now.

Interviewer
You're right.

Participant
Even if for example, you go to schools and ask parents there that not that bereavement, but about anything like, even if it's just child development, you went to schools and then you parents say or ask the I don't know their him, their teacher that if you can put up, you know ask the parents if they then parents winning too. But I think more. I think it doesn't need to be… And researchers do need to like… Think about these different things because that's the one that's the reason why there's more white people views taking more importance, then Asians or black people because even black people don't know about it. They don't, they they don't wear them in to find out about it. Why are people, are more… They have more access to these kind of resources they aware of this kind of things more than Asians and like people.

Interviewer
No, you're absolutely right.

Participant
Like I feel like, could you feel like if I had been white and middle class up classy then I would have got more support throughout my pregnancy and after like well as grieving in while I was grieving and I think I think I would have got a lot more support because as a white person I would have maybe been taken more seriously and they would have known that they need to keep me updated at all times because I'm a white person and maybe I take more priority over the others. Maybe they think that Asian me.. I won't understand things so there's no point even going on for it. But I do feel like feels if I was white then I would've got treated a bit more seriously. And I hope that's not the case and that's just me assuming things and… But I do believe that that I do believe that my ethnicity had a..had some kind of effect on care. Maybe if my son was white and he was so cute blue eyes or something then he would have got more love and attention and care. It does make a difference.
I think we should ask such questions. If we were if we maybe for me, my husband, my husband is like a nice simple person like he won't ask such questions or argue any fights. Very like quiet person. And I think if me and him a bit more dominant and not aggressive, but if we were just a bit more confident and more… Maybe we had put more pressure on the nurses and the doctors that you know we want to speak to somebody like being bit more firm. I mean if we would be more firm and said no, oh I want to know more I want to hold a meeting at this day this time we told them what we want…then maybe we would have got more... a lot more support. They would have taken us more seriously. If we have been more firm I think. Yeah, I do think that if we'd been more firm from the beginning from as soon as we found out there was a heart defect. If we'd have said no, we want regular scans. We want much more appointments with the consultants or who's who's in charge of our care.. if we want much more firm and everything just on the board, then. Maybe things would have been different. Maybe obviously it maybe it was…He would have still passed away. I'm not saying that but…Maybe I don't know he would have had more care. We would have more support.. I do feel like if I don't answer, I do. I do have a lot of regrets. I think that's one hardest things. I do have a lot of regrets. I feel like I should have asked. More questions. Should have been more you know more involved, maybe in the care. I feel like I shouldn't have signed that form fill up. We shouldn't have signed the form to give consent for the operation of him. Should have done more research into the operation or surgery. The consultant that did the… You know the search feel like… So we went so wish I was there more 24 hours like I wish I'd stayed there. Which of those made them like force them to let my husband be there with me. I don't know. I just have a lot of requests I feel like we should have done more. I do think that like we do get forgotten about. Like parents, after the baby that kid gets discharged baby and stuff then that's it. It's over.
Crying..
Pause

Interviewer
Yeah, no. You've made a lot of very important points. I feel like half of my research outcomes of come from your…

Participant
that’s good.. if some help to you as long as I can help you, because then you'll be able to help someone. So if that's the way you think.

Interviewer
Amazing if I were to end… I mean, despite the emotional upheaval, you are in..

Participant
For example, if I did go with the doctors, just general counsellors, or even because their own majority are white so they don't really or their Christian, they don't really understand my culture. Yeah they don't understand because they are not from our culture, not from our background, not from our religion. They don't understand how we see things they don't. You know it's not their fault. Oh, but it's just a thing, isn't it? When they don't want something to pay off our culture and traditions. So and I believe so. I think that's another reason why I wasn't really be able to talk to them or say anything and. Yeah, if we had maybe, but even if I had it feels like a Muslim counselor. Then I'd be able to share bit more islamically like they don't understand my belief some things. But even if it wasn't, wasn't if it was just the Asian or even a black person…our cultures are very similar backgrounds like spirits are very similar black people and Asian, so that probably would make it more comfortable to talk. I think that would help.

Interviewer
did you not have.. Like there are some like through your local mosques and like religious there are. There is sometimes some kind of support available through..

Participant
So if no, yeah, no no. I wish there was. I wish there was more for people for bereaved parents so you know. You know, just parents in general that are grieving or… yeah..
Unfortunately not that I know of there might be, but I'm just not aware of it because it's not really publicized. You know, I feel like death is not talked about enough. Miscarriages is so common, but neonatal is very… It's not really heard off.. this. I'm 34 and I had never heard of neonatal death. I've heard about miscarriage so much and even stillbirths. Yeah, but never, never heard of any like neonatal until happened to me and it was a big shock to my whole family. My whole family or my cousins aunty uncles because they all got really badly affected by it because. It's not very common thing anyways, terminate or death and nobody knows how to… Even myself, we didn't know how to deal with it because… If it's a miscarriage its different because miscarriage… Obviously they all hurt.. all.. and no pain is greater than the other, but in miscarriage you didn't see that child. The child is not actually created and memories too but..because he was here for 11 days, we spent time in. We got to take pictures with him videos.. he moves he responds... So we created attachment and memories. We knew what he looked like and stuff. But if he, then again, if he was older, though, like if he was, I don't know in his, you know. One year may be then maybe that would have been hard as well, so I don't know which one is harder if 11 days or if he was like one year was old or something. Maybe that would have been harder because we didn't… We would have a much more attachment with him…much more memories, you know so I don't know which one is more difficult. Seeing the child for 11 days or for longer think they're just as hard as each other, but my point is, is like death, I think it's just not talked about, especially a child's death is not talked about at all because we're so used to adults death, so we're not used to children's death. And even if a teenager is different with a child like under one like you know it's newborn. Nobody knows how to deal with it properly or started. Talk about it, but specifically in our cultures we don't talk about death as it is, but when its a baby and innocent baby no one knows how to deal with that. Just have to do this as you can really got no choice.

Interviewer
You are…

Participant
I don't know. I hate when people say, oh you're so strong because I don't understand that you know a lot of our families at all. You're so strong Mariam so sorry but I don't understand. I don't hate you but I just don't understand it. Yeah it's not hate so it's not and I don't understand it because how am I

strong because I'm always crying all the time.. How can I be strong? Do you know what I mean? Like I don't feel wrong but right?

Interviewer
Yeah no, but you don't have to be strong. You have to process your emotions. I am mean in the way you've shared…

Participant
no no…I just wanted to help others. I don't know the best way to help others is free helping you. Good thing that NHS is multicultural because those…I'm saying that and it's really it's it's it's a very good thing, we're lucky that this country that we've got such a multi cultural population that a lot of the doctors nurses are or from different heritages, different cultures. So those staff they should take advantage and then NHS itself should take advantage of having stuff like that where they can use their heritage. Their background for a good purpose and support the people from those same ethnicities you know the patients that are from say different ethnicies for example. I had one of the nurses and that was in the unit NICU…and she was Muslim and she should do… I feel like being a Muslim from same background as me she could have given us more support like maybe understanding that our understanding might not be too good of you know the NHS or these procedures and what's going on and we don't know the right questions to ask, whereas maybe a white counterparts they might know a bit more about what to ask, what's going on, you know what their rights are in the sense of what rights they have to access any information, or who they're allowed to talk to. You know, you know, you understand, like white, people do not get more, I guess, so that's what maybe assume so. I wish that I do wish that knowing that she's from the same community as me she was in that same room she could easily have just…I wish she came up to us and just spoke to us. You know, make sure that you know what you need. Any help you want me to not asking me if I'm do you want to know.. just said her she should've said herself that I'll just go into bit of detail about you know his treatment was going on and understanding that I might not have the understanding being from that community she should kind of understand that she should just support somebody from her community, specially knowing that her family is probably from same community. Just she should think these people..should think that…what happens in their family, for example, that their family might not be as understanding how their family would react to that? You know something like this. They should treat others the same way. If you know what I mean, that makes sense. So that's why I just believe that. Having such a multicultural workforce in NHS it should it be, you know it should be like welcomed and taking advantage of the fact that there are some different races languages spoken that used that as their strength and you know, use those that diversity is a strength and get those members of staff to work with those communities. Or if they see, for example, in maternity unit. If there's like a Somalian lady and her…isn't very good English, and if there's a Somalian nurse working in a different unit then just ask her that. Is it Ok if you just want to get time.. Can you just come at this time and just help this woman? Just explain to or just translate you know or just give bit of support. Even if it's not asking for too much, especially in such a diverse workforce in NHS they need to use as advantage. It's not, you know, being picky, and I know there's all this political correctness about you're racist, you don't want to offend anybody, don't want to single anyone out and UM you know obviously this a lot of sensitivity. I found that but try to see as they should try to see as a strength because we're quite lucky. Like I said in in the UK we're very lucky to have such a diverse workforce and other countries don't have that like as much as we do. So we need to use as advantage. Thats it.. I think..i hope I have helped you..

Interviewer
No, yeah yeah, a lot..

Participant
Thanks.

APPENDIX 11- INTERVIEW TRANSCRIPT – NURSE ANNE

Study introduction already given to the participant. PIL and consent form shared.

Interviewer- OK, and I will also be audio recording.

Participant- OK.

Interviewer
So this study is basically about lived experiences of professional so nurses and doctors who work in the new Natal Intensive Care unit and their experiences around working with babies were going to die and their families so newborn death essentially. The idea is to just understand how your experiences have been when you have been in situations. What are the what, how your journey has been when you have worked in there Nice and in similar situations. So I I have a few questions which we can start with. There are of course no right or wrong answers. The aim and objective of this is just to understand your experiences, so there is no right and wrong. Whatever you have experience what you have felt, thought, that is what I want to really understand. I have explained to you the confidentiality part. Of course, everything that we discuss here remains confidential, and only the anonymized data will be used for as verbatims for when we write papers or for the reports. In addition to the recording, I'll also be taking notes. So if you feel that I am not listening, I'm just taking notes in my diary.
Participant- Yeah, no worries.
Interviewer- So do I have your consent to begin the interview right?
Participant- Yep. Yeah, of course.
Asks demographic questions [details removed to maintain anonymity]

Interviewer- OK, so just to start with, can you describe a typical day in the NICU.
Participant- Uh, so since we since we arrived to the shifts, right? So yeah, so.
Interviewer- Yeah. Kind of babies you get etc. just a typical day
Participant- We usually get the handover of all the babies in the unit like. what's a the condition the situation. Uhm, which babies are the more unstable and what babies are ready to go home? And then based on the skill of the nurses will get allocated to the babies.
Uh, and then we go. Once we have the baby allocated to us, we go to the units and we take over from the nurses looking after that baby that is UM, looking after the baby at the moment. So we have a very detailed handover like we have half an hour to have all the details.
And usually once I receive the baby I just start doing all the check-ups like the emergency equipment, preparing the feeds for the day, communicating with the medical team and with the parents. And see what the plan is for the day with the parents, what time they are going to come in, what time they would like to have a skin to skin, when we need to change the nappy so we can actually kind of plan the day with them as well, involving then as much as we can in everything.
Obviously there are emergencies that you cannot control, are more complex. And then that changes quite a lot sometimes, or if the baby gets worse. And you need to adjust and you need to like Kind of tailor made the care of the babies around that situation.
Uh, and then Yeah, if everything goes fine and your baby is OK…Uh, obviously I'm talking about and on a baby that is not dying like who is stable.. We yeah, we try to involve the parents as much as we can.
And we try to do skin to skin. We try to you know that we give them time to bond with the value because it's quite difficult when you are not with your baby every hour and you are feeling, you are

sick or you cannot move properly. You need to come from the maternity ward in a wheelchair and you are depending on other people to bring you here to express and all that kind of things.
Uhm.. Yeah so yeah. And then at the end of the day then we hand over the same way they have handed over to us. We hand over to the other nurses looking after the babies, so it's continuing care. So if there is something I haven't done during the day, I make sure that the nurses is taking away from me or at least knows about it. So good communication with everybody.
And then there is a baby that this time that's obviously more complex, uh, we could. I mean, it depends on what stage you start looking after the baby. We basically try to give as much privacy as possible to those parents. Uh, so if they are, I don't know if you've been in the ITU, we have big room with all the babies in there and obviously you don't want dying baby in the middle of the room, so we try always to change to more private room. Uh, ideally where the babies along with the parents and with the nurse because when a baby is dying, and usually you only have one baby at a time..Usually so you can't actually…you give the best care possible and like tailor-made care around that family because it's not all…It's not at that point is not that baby you are looking after more, it's actually the family and the that you are trying to give I think more time for the family to bond and I don't know, I think, UM we actually do it quite well, I think. How we try to give them privacy and give them time and explain to them, how we communicate with them on..this is going to be important even because sometimes the parents don't want to and I understand because this..it's difficult to bond with her baby that's dying or..
Interviewer
They don't want to spend time?
Participant
There are, there are some..it depends on their parents. I had a situation where it was quite hard for us, I wasn't directly looking after the baby, but the unit was not busy and I was the admission nurse. That means that I just carry the emergency bleep and I go for emergencies, admission nurses don't usually look after babies during the shift, and there was another nurse looking after the baby.
And that family didn't want to see the baby at all.. so we were calling the parents saying do you want to come because then she's going. Uh, and they were like no, no, no, we don't want to see the baby, so that's, at the end it was me and the other nurse we are holding the baby while she was dying.

[Participant tearing up]

So I and it's it's easy to judge, but I think, UM you know everyone reacts differently. It doesn't mean that, uh. they were not grieving. I understand that they didn't want to bond with the baby. Yeah, and there are other families that.
They...
I remember 1. actually that's a I was looking after them. And I think it's one of those families I'm thinking about that we can contact as she was a very preterm baby. Very bad prognosis on the baby, we decided to do withdraw care. And they were by Irish, very Catholic family. And it was before coronavirus, obviously. And they wanted the baby to be baptized and they wanted all the family to meet the baby. So we try to manage to for all the family, like very long, very big family to come into the unit and see the baby like a two or three members at a time so they can all bond and see the baby and you know support the parents.
Uh, and do all the rituals that they want to do, even if it's not baptised..Whatever it was they want doesn't have to be Catholic, or I mean it's really useful.
Interviewer
Yeah, you said it's easy to judge?

Participant
Yeah, I mean it's very easy to say, oh, I cannot believe that they don't want to see the baby or they want to, but at the end of the day, you know their grief.

I cannot imagine what it is, and people grieve differently so. As nurses we need to really empathize with them and. And just respect the decisions cause…And it's not really. I mean, obviously you feel sorry for the very bad ones…The remaining ones are the parents and. I don't know. Everyone tries to cope as best as possible with things. So it's.

Interviewer
So in this situation you said you were holding the baby, how? How does that make? How did that make you feel? Do you remember what your feelings were?

Participant
Yeah. Obviously we have sadness and Sometimes anger of why this is happening to these babies and. You know, I, I think it's the personal process that you go through with every death because you think you will get used to it but you don't? Uh, and is a different process every time I think. And yeah, and in that situation, I specifically was very very emotional for us because we were me and the other nurse we were the ones with the baby when she was passing away, which is sad that people I don't know your parents don't want to be there with her. At least we were there and someone to to hold them and to come for them at that time.
I don't know the feelings that fit inside.
For me now, it's harder actually. After I have a baby, I thought it wouldn't make a difference at the beginning but it does..So, you kind of imagine what the parents are feeling, but you cannot imagine the feelings right? So it's…

Interviewer
So now that you are a mother…you feel?
Participant
Now that I am a mother, yeah, yeah, I feel different. I don't know how I would react. How, Oh yeah. I actually had my now… some parents thinking back the way they handle it in the way they behaved and the kindness that they show to everybody at the moment. No, because it's not that easy moment to be kind to anybody, especially you are.. I'm just thinking when I had my baby, my moods and my hormones, and you know the way you get the mood swings and everything. How in that situation? How can you cope with?
The death of your child is it's… I cannot. I don't know. So it's it's really yeah, I think it's really. I mean is the worst thing that can happen to you.

Interviewer
Yeah.
Participant
yeah.
Interviewer
Did you feel any form of stress when you were in such situations?

Participant
Yeah, I mean it depends on the situation. I remember. I remember one. It was one of my first death that I actually look after a baby and there are two kind of deaths. The expected ones that you go into the shifts, you know in that the baby is dying and the unexpected ones… So I started my shift. The baby was stable, was doing fine and then that baby..he started to get very very very sick, very very unwell and within six hour the baby was dead. That was really that was one of the worst times that I…One of my work shifts, honestly.
You keep wondering what you haven't done, what you could have done, what you did wrong, what? What are you going tell the parents.. how the parents are going to react?
Uhm, how are you going do? I don't know like they after that because those parents didn't have time to say goodbye to the baby it was the middle of the night..we were trying to do everything for the baby

and at the end of baby pass away to know intubating and all those things, which was a very horrible way to die. Uh, and then when the parents came.. you kind of need to give them time with the child in… and get their mind around what happened because when they left the day before, the baby.. it was fine. So it's it's. It's quite.. for me that was really, really hard. And I think it's very important when that happens and I was a junior.. I was like very new. And the nurse that you have like an nursing in charge that you have in the shifts, they kind of if that person supports you and supports the parents, and kind of takes over from you when you think you cannot handle something or comes to you and say go for half an hour because I remember that night I didn't have a break and it was six in the morning and I was actually crying in the hallway and she said go have a tea and cry whatever and then come back. Take your time so that's something really important as well.
The kind of person you have in charge of the whole unit, the skills, the leadership or.
Communication. I mean at the end of the day.

Interviewer
That helps you process?

Participant
Yeah.
I mean, when you have when you have a person there guiding you or supporting you, even whatever experience you have because you can be very experienced. And then maybe because you're also your personal situation. I think also influence your mood and how you are on the shift. Even if you say yeah, I need to forget about my personal things and focus on this sometimes… you know you are just..you are human. You cannot put that aside and sometimes it is these things hits you harder than others. And I think the person the team around you, not only the nurse in charge, the team around with your colleagues and everything that makes a lot of difference on how you process and how you handle situation.
And all that.

Interviewer
So..when you have gone through such situations where you feel a lot of distress, do you seek any support?

Participant
umm yeah..

Interviewer
Or any support that is available for you…

Participant
Yeah, yeah, in that specific situation with a baby really, I really had very hard time afterwards because the same nights.. I mean, I think the whole team was there when that baby that I was looking after died and at the same time we had a crash call.. in the delivery room and the baby also died. So there were two deaths in one night, and the team was so they were asking who needed psychological support. Uh, because it's not easy to come back the next day after you have this horrible shift, uh, so. So yeah, I kind of asked to speak with a psychologist just to, you know, wind up and yeah try to get some help on how to process everything.

Interviewer
Was it helpful, do you think?

Participant
Yeah yeah because yeah. And also talking to your colleagues as well because you keep playing the

nights in your head like what have I done? What I could have done? All the guilt that…uh, and sharing that with the psychologist and with your colleagues, you realize that, okay, that I mean you did your best. You did what you could. And in a way, it helps to feel better because…you know…

Interviewer
Otherwise, you feel…

Participant
Yeah.
Yeah, exactly, I mean…Yeah yeah I. I mean, I remember the main thing that remember with that baby is thinking what I didn't do what I should have done, what I should have done this earlier or yeah, and I think for the doctors at that time as well was very because I remember they had the baby that died before in the delivery room and then this happened and they were like we were doing CPR and they were like I cannot believe this is happening again.
Like I don't know..things that are stuck in your minds are like very difficult to put aside sometimes.

Interviewer
Yeah, and you still have to continue caring..

Participant
Yeah…

Interviewer
Doing everything.

Participant
Yeah, I think it's difficult to come back the next day, but then you also see the babies that get better and that go home absolutely fine after a very long journey in the NICU. It's so… that's very satisfying and…Obviously. When I deal with some very..difficult place to work sometimes, but..but also is very well. Yeah, it's.

Interviewer
Balance?

Participant
Balance. Yeah.

Interviewer
So seeing a baby recover.. Does it help you dealing with?

Participant
Yeah, the. Yeah, to deal with all these. But they send this and at the end of the day, I think you know the deaths are very hard. But the I think it's much harder to have a baby with disabilities, or knowing that the baby is not never going to walk or never going to talk or not going to, you know, have a normal life. I think that's much harder than…because I remember one parents they thought the baby.. it was a very bad HIE..a very severe, and the parents thought that he was going to die once we extubated the baby and the baby survived. And, UM the doctor, what we're telling them OK, she might never talk. She might never walk. She might never. So the parents, the mother told me I wish she would have died, so sometimes it's…you never know, but you didn't know what's waiting sometimes.

Interviewer
How did that make you feel?

Participant
Sure. I really understood her, you know? Because…Yeah, I know it's hard. It's hard to say I mean. I don't know. I don't know this. The state of mind of the mother to say that, but I really understood because I think about it myself sometimes. I mean, if it's not, it is not going have a life. He is being selfish as well.. because it's going to absorb my life because he's going to need it. He's going to need 24 hour care. What's the point, right?

Interviewer
But there are some parents who don't want to withdraw care and no matter..have you had…?

Participant
Yeah. No yeah yeah. It doesn't matter what the doctors tell them, they don't want to withdraw care. And. And I think actually that's… That made me feel…. Sometimes thinking that…Like more, not sad... Sad or angry sometimes… sometimes because that baby is not going to have a life. So, so I guess you just want to keep it. He's going… I mean he might die in a couple of years so.I don't see the point. They keeping that baby alive, making him suffer. Uh, keeping a tube down his throat just because you want to keep him alive. It's selfish. The baby is in pain..so yeah.

Interviewer
It makes you feel sad and angry…

Participant
Yeah, yeah it depends. Depends on the situation. Then but of course, as I said before, I mean… Yeah, every time that happens is a process for the last because you… obviously you cannot let it…you cannot say anything. You can't judge, you just need to support the parents with the decisions they make. No matter what your beliefs and whatever you are feeling..I mean that's…that's a process for you to digest, maybe after the shift, and think about but...
Uh, But yeah. Yeah, because as professional and as caring for them because at the end of the day, it's their baby and I don't know how I will react in a situation. Maybe I will be the same…

Interviewer
Yeah.. You said that no matter how many experiences you have, you never get used to…these situations

Participant
you see everything. No, I don't think so. I mean.. Maybe you kind of with years... I don't know because they do do kind of compart…. how you say that…

Interviewer
Compartmentalise?

Participant
Compartmentalise more, uh, because you've seen so many that. Yeah, I want to keep your completely… Your feelings completely away from from that. But I think it's quite.. for me, it's quite difficult. To do that at the moment.

Interviewer
yeah and you said another thing that you know your personal situations also influence what you are feeling. Can you elaborate on this?

Participant
Yeah, I mean. I mean, do you go into the shift and you think, uh, OK, you try to forget whatever is going on outside in your life? For 12 hours. because obviously you need to focus on what you're doing and you cannot be thinking about your life because you are looking after babies… uh… but obviously you know if you haven't slept well because you have so many problems or if you are waiting for an important call or whatever, or I don't know, 100 situations in life. Well, it's obviously and you try not to show it, but it influences on your moods, you cannot…Sorry, you cannot avoid it, it's I mean it's human nature and sometimes even situation with you are with the parents and with their baby and just you don't try to show it, but then you are very sensitive with your colleague because she has told you something and you snap out there or something like that for me. So obviously…I don't know what you'd say… It's a..as much as you try to to to…forget about them and you can't…overnight. Well then… but yeah, I mean. There are days that you end up in a better mood to..you know, you know, calmer mood to deal with some things and some days you are not so nice you go… I go into the shift and if they tell me you have a dying baby, I would say you know I cannot do it today and some people do that.. at the beginning of the shift or you arrive and then you say you know you are always usually...I was usually in the NICU and if what whatever reason you are not feeling well, I can say can I go to the low dependency because I'm not feeling really well so. I think we all need to adapt a bit too everyone's feelings as well..yeah…

Interviewer
And your work environment is supportive?

Participant
Yeah..yeah

Interviewer
To allow…

Participant
Yeah. Yeah, yeah, actually. One of our colleagues and was very close to me.. and he had a lot of mental issues. It depression and anxiety in yeah, that's so. He usually and he will come early in the morning whenever he had a shift and say OK, can I? He will choose the babies that he wanted to me to work with. And that went on for a long time. And you know, there are people that complains and say they were saying things about that, because it's not fair that you can choose no if you think about it, it's not fair that you can choose the best.
Baby or parents to work with. But some people need some more support, emotional support, psychological support than others. So I think that's very important for all of us to keep in mind, because now its him and tomorrow can be me because I am. I don't know, I'm depressed I whatever I still need to go to work, so it's a… I think that the whole team supports that is quite important.

Interviewer
So he's he had anxiety because of…

Participant
No, I mean he had anxiety and depression… I mean he killed himself in in April. Uh, so yeah it was. He had issues in life, but obviously. Working in an ITU… And one of my last conversations with him, where if you wanted to move to research because he couldn't cope with some days with working in ITU…So that. I did not mean his problem were not related entirely to that, but obviously it influences on how you feel at the end of the day.

Interviewer
If you are already feeling low and then...

Participant
And you know, yeah, ITU environment. It depends who you work with can be very difficult. There are very…There are people where he…Not bullies, but they can make you feel really bad.

Interviewer
People as in?

Participant
Like you know, some nurses on, or the nurses, especially, especially if you don't do something, or if you don't do things the way they were used to do it, they can put you down quite…quite easily..If you don't have a strong character or you want to ignore what they're telling you that it can be quite hard. You know every day telling you you're not good enough for you or you are not doing this well or you should have done this this way or you forgot this again. So it's can be.. Can be…..

Interviewer
And this combined with if you have baby dying….

Participant
Maybe dying… I mean. When you have a baby dying. Yeah. I mean, in that day they don't usually come to you to tell you anything, but obviously depends on your whole in your mental well being. How you if.. I don't have. I have colleagues that. When you make one mistake, one big mistake if you will… Would have unusually medication. Sometimes you get pinned down. Like the person who had the mistake. And then you are not good enough for anything else and it takes a long time to build your confidence again and to for people to come to trust you doing things and. When…When you have a baby dying.
I mean. Do you know what happens there are people that usually like it. and when you know that babies dying and the person would get allocated to the baby that you know that people are not really good at palliative care Well that I'm not.
And that's good. because of the way of the way they communicate or experience.. You know, so I think the nursing in charge who allocates have that in mind. I think most of the time…

Interviewer
OK.

Interviewer
And what about your own personal beliefs, like your cultural beliefs, religious beliefs? Do you think they have any influence on how you deal?

Participant

Yeah, no. I mean, I'm not religious. I'm not a religious person, but uhm. You know I, I just tried to respect what the what the parents want. So I don't really show or I don't think about religion when I looking after baby. I mean I'm not of my own beliefs. I mean I your values or your beliefs is not something that you can't remove completely, but I don't know.
I just try to respect what the parents want to do and, uh, me… I I do remember there was a situation, that's why I say I ask you about the religious thing, because there was a nurse looking after baby that was dying.I I wasn't… She was very Catholic…the nurse.. And I think the parents were Muslims or something and I saw her doing the cross [shows by hand…on the baby's head] in the child when the parents were not there and it's really annoying because I was like why would you do that? I mean, I understand you are Catholic and all that, and that's you know. Hey.

Interviewer
Why do you think the nurse did that?

Participant
Yes. Because of her, I mean no one was in there, parents were not there.. Yes, I think it was just for her own beliefs that try to do something for that baby to I don't know…to go to heaven may be I don't know.. But yeah, when I saw her, it really annoyed me. And.. That's that's why I don't know if it's easier for nurses that are not religious to deal with them…With the babies dying. Because I mean, I don't know I had a, but I guess if you are very Catholic or very Muslim or whatever…It might be more difficult to see other kinds of or or see a baby without having being baptized or may not know before they die. Well, yeah, for me personally I try not to not not show anything. Oh yes….To give the parents as much information as they want.. So have a informed decision and not to show my feelings, but I I understand it can be difficult when you are religious.

Interviewer
Right, so if if not on how you provide care, but how does you said your values you can't remove. So do you feel that it helps you dealing with?
Any of these values or anything?

Participant
Yeah, I mean. I mean, yeah, I mean my values are my values like I'm not, as I say I cannot remove them, I just try. Whenever I am feeling, whenever I am dealing with the process myself off the death of their baby, I'm I just try to be..I don't know. Like I don't know how to explain this..

Interviewer
Is there something that makes you feel?... Better…

Participant
Umm [Indicates not following the question]

Interviewer
Like you said, you also said this point that may be nurses who are not religious. It's easier for them because maybe they don't believe in God….

Participant
Yeah.

Interviewer
So you don't know….

Participant
That then treat with religious rituals or whatever.
I think, yeah, I think…Yeah, I mean, I'm I'm very personally for me it's not an issue.
So I, I mean, or for any nurse… whatever the parents wants to do, I don't really care what. As long as the baby is, you know, or I I can see parents having time with the baby, bonding with the baby, grieving with the baby .. You know, try to support them as much as possible. I think for me that's like more important than anything else, so the other things kind of.
Really, I don't care about them, so it's more about when I am looking after a baby like that, it's more about supporting the parents, really, obviously the baby, but the baby… you try to make the baby comfortable as possible, try to change the nappy with the parents. Wash the baby with the parents.. Uh, give the baby to do skin to skin with them or just to hold them or… I I remember 1 situation at [Names the hospital] where we took the baby outside in the balcony with the parents, which was very

nice and very positive way there. Uh, so those kind of just try to adapt to what the parents would like to do in to help them grieve and to help them go through that.
Not there.

Interviewer
yeah.. so… Just trying to…when suppose if there is one nurse who is religious, do you think her own belief in her God, whichever her or his God, do you think it helps them in dealing with how they process like is…?

Participant
Yeah, no, definitely, I think. Yeah, whatever it doesn't matter at the end their religious.. what religion they are, but I think it helps them think… It says something else… And to process the death of the baby.

Interviewer
This is not how you…

Participant
No. it's not how I process.

Participant
So that's why I'm saying I don't really know, but, uh. I never really thought about it that until now. Uh, how they process..it makes them feel better. I mean, I think in general. When you are religious it helps you. With things not only with the death of a baby, but and then yeah, I mean with me, it's not. It's not how I how I process.
And I give more importance to other things, but I mean, it doesn't mean that the other nurses don't need it there. It's just they. They are internal….You have yourself.
And I don't know how to say this.. how you process it is just different.

Interviewer
Okay..

Now I just want to understand. So what happens when a baby dies? So you had started explaining about… Uh, the unexpected death so we can discuss that first and then come to the unexpected ones. So like when you contact parents, how you do just… what really happens? What goes on in that situation?

Participant
In there…Yeah so. Yeah, well, I'll just go through that particular one… So what happened there and why it the nurse in charge when the way baby was starting to deteriorate..the nursing in charge called the parents to say this is happening… we don't know why, but it would be good for you to come here as soon as possible because they were at home. So obviously you're starting from parents.. What's going on? And if they can come here as fast as they can because we don't know how, how much time we have?

Interviewer
Why was this baby admitted?

Participant
It was a premature baby, but not really.. It was a IUGR. So that's another factor that. So it was preterm and IUGR. I think it was like 2 weeks old which is…You know you, for the parents its harder because

they kind of think that she will be… She will be fine after the first few days of uncertainty. And that baby was sepsis actually.
And…Yeah… So the nurse in charge called the parents. Parents arrive after an hour or something because they live quite far away. And you know, in the middle of the night, as much as you run. And so when they arrived the baby was they just..she just passed away like 5 minutes before. And, UM. Yeah, we were there. I was there with another nurse, the consultant, the Junior Doctor. And then nursing in charge.. we would always, never on… It was like, uh… There's like 5 in the morning. And we were on our feet the whole night and with no break. No dinner, nothing. And you'll see those parents coming in… And the mummy..we didn't even have to say anything. The mummy already knew that the baby had passed away. So when she started I mean..when she started crying, the feelings…

[Participant getting emotional]

And then these baby was in the middle of the room. So I mean, it was in the night and there was no other parents, it was just his stuff. But obviously you want to give privacy to that to so we started transferring or the baby. And then you go through… You need to wash the baby, we dress the baby we make everything ready we have. This, uh, memory boxes where we take her little bit of hair from the baby and like an imprint of their … umm…

Interviewer
feet?

Participant
yeah, feet And usually the nurses we do that, uh, I tried to offer it to do it with the mummy. She didn't want to…but I I did it anyway because I think in the future they will want to have something from the baby. So we do it and sometimes they don't pick it up. But there after a couple of years they call and ask whether we have the box or not. So I think it's something that's very valuable for them. In time and yeah, I mean…the process of telling the parents of course, it's I didn't. I didn't do it. It was the nurse in charge who called them and then the consultant explained everything to them. I know you said you are there witnessing and we are the one looking after baby. So that's…It's quite and usually nurses. You know we are the one that deal more with the parents and they know us and they come to us later to speak with us rather than with the consultant.. because the consultant they see them like 10 minutes a day or 20 minutes a day. So at the end it's it's more with us. Yeah, it's… And then for me that was really the worst.

When you have an expected one, it's like you have time to do things and you've like you give the baby for Cuddles. Even if the baby is ventilated and has a lot of things, you give the baby for cuddles with both parents. Or if the grandparents wants to come in and see the baby in.
To wash the baby, change the nappy..things like that make the parents bond with the baby that's…it's it's beautiful. It's beautiful to do it in a way because you are giving the opportunity for those parents. So now there baby…But some…. Yeah.

Interviewer
Would you say it's easier on you?

Participant
Umm yeah.. For me personally, its easier, the transition. And I mean, that's it. But yeah, when…when you have that that time because time here is just precious.. It's the most important thing and you have time to do all these kind of things and… yeah, it's it's rewarding in a way. because I mean as hard as it is at least you have done something for that family.

Interviewer
It feels rewarding…?

Participant
yeah, in a way it feels rewarding, yeah

Interviewer
Can you elaborate?

Participant
I don't know. I mean inside all the situation that is baby dying that it's really hard and he personally for you can be whatever in for the parents.. Uh, but you are there communicating, their advocates? I don't know if that's the right thing to say. The advocates for the for the family and you're trying to make things as clear as possible for then telling them step by step what's happening. What's going to happen, what they can expect…yeah, and give..just give giving them time with their baby, providing that that time with them.
I think that's really in valuable for parents, that they have the time to end the person helping them to do it to support them, I don't know…In the in the process.
Yeah, I think it's rewarding..Yeah, I mean now…sometimes when I finish. Whenever I had these, as expected, that when I finish my shift, in spite of everything I feel well thinking that the baby at least had the parents with him and then the parents had opportunity to hold their babies for as long as they wanted to hold the baby. So yeah, uh...

Interviewer
Yeah, and have you had any experience of working with parents who don't want to withdraw care? So who don't agree with?

Participant
Yeah, yeah, there was actually another HIE baby. At [Names the hospital] and so this mummy..the this was the second child. The first one was a extreme premature, and the baby survived and she was fine. They told her with the first baby they told her that umm.. the pregnancy was really bad and it probably they will die because it was I think 24 weeks when their first baby was born, so…and the baby was absolutely fine..so I think.. She..when this baby had very bad HIE, it was very bad. I think sort of she thought the same was going to happen. That sometimes doctors are wrong and you never know…so she didn't want to withdraw care. It was conversation with her, the consultant with her had for a very long time. And then she was always coming to the nurses, to me or whatever whoever was looking after the way we saying..they don't know everything. They don't know everything. And I'm praying I'm praying for my baby and my baby's going to be fine. And I don't want them. And she was saying I don't want them to withdraw care so that's… And I was.. one of the situation I was telling you at the beginning that I understand the mother but it's not the same situation with the preterm baby, and this is not and this baby is going to be.. he couldn't even swallow the secretion, so that's you know, you know the baby is going to last for a few years and that is where baby would probably pass away and it's not fair for her. Not fair for the husband or fair for the other child. So its yeah…It's a hard situation to watch to be honest.

Interviewer
So what happened?

Participant
So I mean so the baby…what happened with the baby…because I think I would definitely…. but now I think the baby pass away. Actually he was a few..because he got a bit better respiratory wise and

he was on CPAP for a long time..and then after a few months of in and out of the hospital the baby he passed away, I think.

Interviewer
So they took the baby home?

Participant
They took the baby home.. I think he was home for a few months but in and out of the hospital with pneumonia. And I mean those parents..but yeah, I mean.

Interviewer
So you felt that situation…made you feel its unfair?

Participant
It's I, I think it's unfair for everyone. And you cannot… Honestly, I understand the mother like…but maybe just ignorance from probably just ignorance from part of the mother or had religious things whatever but…you know you cannot. it's hard for me to know I have hard for me to watch because I know how what's going to happen with the baby was going to happen with the family, but….

Interviewer
How do you? How do you deal with that in that situation with the mother and the father?

Participant

Just. We're just trying to support, I mean. Whenever they ask something, uh, you try to be as clear and as truthful as possible, even if it's you know it's uncomfortable for them to hear because if they ask you, will he ever be able to eat on his own? And the doctor has said, probably not…Probably not, surely not, and…I mean yeah, you you try to be as truthful as possible, but at the end you cannot force. Or you cannot … You don't want to make them feel that parents guilty for anything. You know that they decide to do so. Yes you try to support them however you can? Think you know nurses in that way we are more…. I mean, they have discussed that with the consultant and the consultant is the one that… Not push, but you know lay the facts and and give their professional opinion on what's better to do with baby.. But in but nurses,, I mean you can have your opinion, but you're just..you're just there to support their parents with whatever you decide when they decide to do.

Interviewer
Trying to keep this balance of supporting but also telling the truth and not…making them feel guilty. How… is it hard sometimes?

Participant
Sometimes yeah, sometimes it is, but. Yeah, sometimes it is. And uh…yeah, I don't know why sometimes you ask you are just there doing and explaining to them what you're doing and trying to meet to help them with everything. But don't engage…so no, we don't engage much. I remember that particular situation. I wasn't engaging much with the mother because I didn't know what to tell her… Uh, you know when she was asking me things about the baby. And I know it's not, it's not nice but yeah, I guess that's why you…we have engage more with sometimes and others as well, I mean… As you click better with some parents and others, and I think this beliefs is or these values for this, whatever, that's what makes…your relationships with the parents.. Yeah, sure…Right so. Yeah as professional as I try to keep it at that. It's there, it affects in a way….

Interviewer
And are you involved in the bereavement support which is provided to parents after so this is happening during..?

Participant
Yeah. No. We are usually not involved in that, so once we've done, we prepared the baby we've we've done all the paperwork and everything. We kind of not see the parents again unless they come to visit. But we are not in touch usually with them. Or anything? Yeah, in a way I mean…I don't think the parents want to keep in touch. But but yeah, I think that's more on the psychologist, and I don't actually know for how long. So they can give support to that part its from the neonatal team. Yeah, once our shift finishes and baby is taken away. I actually don't know what happens after in regards of family support.

Interviewer
OK, so your involvement is till the baby is taken away?

Participant
Yeah, sometimes we take the baby to the to the morgue.

Interviewer
OK.

Participant
And that's it. We finished the paperwork that we need to do it.

Interviewer
OK, so before before all of this happens…you said you come help in preparing the baby we you do. So do parents get involved in that process?

Participant
Some parents do..yeah sometimes
Yeah but yeah. Yeah, we just, you know, wash the baby dress the baby. And make them look nice, yeah..

Interviewer
Do parents bring the clothes that you dress the baby in or how does it work?

Participant
Sometimes they bring it and they bring everything they want the baby to wear and all that and sometimes we just use what something nice that we have there.
In my personal situations mean… like 2-3 parents were really involved.. I didn't have much exposure to have like in total maybe 6 or 7. So I remember two or three that they were really involved…And they would be..they would bring in everything for the baby. And I mean I was just there with them. But they were the ones doing everything. And they prepare everything.. I was just like I just removed the tubes and stuff like that and they did the rest.
I know some parents who don't want to do anything at all and so it's us doing everything like getting them, dresses, washing…

Interviewer
That makes you feel?

Participant
The process.? Yeah, yeah they say when the parents are there and they you can see that they have bonded and everything. It's it's nice. Yeah, when it's not. I mean I only had that very bad experience… when the baby that was looking after died so unexpectedly. And I was the only one. I was alone preparing the baby. That was really down..yeah, that was really hard for me. You preparing, dressing the baby happened, getting the tubes out and getting the hair and you know…yeah…

Interviewer
Do you? Do you feel impact of these? You know these hard ones. Do you feel that they impact your personal life or have you?

Participant
Yeah.

Interviewer
Felt…

Participant
Yeah no, I said sometimes…Like what do you mean affect my personal life in terms of beliefs or??

Interviewer
Uh, I mean yeah, just affecting you…you know, for example, if you say in maintaining a professional attitude or the distress that you experience if that affects you personally…

Participant
Yeah, probably yeah. I guess what I'm…for a while it did.. It it it's like… It's a bit silly, but and yeah, the IUGR baby today…A couple of months after I will look after them. But and I and I still think about it. You know? Like things that are stuck with me like I should have done this earlier. And I think…I don't know for me was one of those experience that I think never will go away because I really felt bad. And..and because I was quite new. I don't know. I thought I was all the time thinking maybe if I was not looking after the baby would be alive because I don't know, you know. Being being so new looking after that. Maybe there was already stable in the beginning… Maybe they will have picked up earlier, or if it would happen to me now that I have more experience. So you know it's. But yeah, I think it's definitely it affected me. And personally, of course….

Interviewer
When you communicate with parents, when you first tell them about a poor prognosis or…
Can you elaborate? Can you tell me how experiences of that are…Communicating.

Participant
yeah, I mean usually because they usually speak with the doctors first. and they come to you knowing what's going on and it's from do they seek more like…I don't know questions that maybe they haven't asked the doctor or your opinion on how the baby will do or your experience or one other babies. And so it it's hard you know to answer truthfully, because obviously you..I mean, if you cannot help to feel positive and to…they are babies, so you…But you you cannot. You can see babies that do well, but you know… You cannot tell them that it might not be the situation you don't want to give him false hope. At least me, and so it's it's you know, sticking to what the prognosis is sometimes can be can be hard because I think. We are intrinsically positive when it comes to babies and you think they are going to do well and…but yeah, no, it's it's, uh, it's complicated, so I think.

Interviewer
Is a very interesting point you have made that we are intrinsically very positive….

Participant
You know, I think when it comes to babies, I mean it's… yeah.

Interviewer
And you think even parents are…

Participant
Yeah, I think you know deep down…I think.

Interviewer
Managing this with false hopes… ?

Participant
I mean. It's it's complicated to manage the false hope, yeah…

Interviewer
So that's a very interesting thing..

Participant
Yeah… [Pause]

Interviewer
Uh, OK, I'll just check. I think we've covered most of things, just one, maybe one last question. UM, you've talked about the support that you received at your workplace, but…
If I were to ask you if if there's anything that you think can be done more or something you'd like to change…

Participant
Uh, do mean within a team if we have like…

Interviewer
With inside the hospitals that you work in within the organization.

Participant
Yeah, I think we we are quite good at… We have usuall,y when something goes wrong or like in this situation, when we had the night of the two babies that died, we had like briefing like what we did? Well, what went wrong? What we could improve? And, UM I think they are quite well at listening to the staff and trying to change things… And I haven't.

Interviewer
Is this something which is done with doctors or is it a separate for doctors and nurses?

Participant
Uh, in this specific situation we did it all together like. I mean the team that was involved in each step. We were all in the same in the same group and we were.
Sharing experiences and thinking what could be done better? What was really well done and what can improve? So I think I think. They…. Willingness to do things well are there and in my work for a while.. sometimes if you try to change something, you find a lot of resistance. I'm not talking about a situation specifically, but in general… But I think the managers are quite good at listening and try to, try to change things for the for the for the better.

Interviewer
You had mentioned about the bullying aspect…

Participant
Yeah.

Interviewer
But do you think this is something?

Participant
Yeah how we treat our colleagues that are, I think right yes, OK.

Interviewer
Because this is.

[Interview interrupted]

Participant
I mean are they? No, I think you know when you first start in a in a neonatal unit it is hard enough. And the last thing you want is your….You just need guidance and support and everyone that is there is really or most of the people that are there aren't really willing to learn and really to do. Willing to do a very good job so they just…some people need more support than others, and that's it. You find that in the school and everywhere, so you just need to adapt. Not adapt but try to help everybody to navigate and not to be very rigid on how you do things. As long as things are done properly and it's …Yeah, I mean it's just I I understand when they are… Working for 30 years in the same place, it's very hard to change your way of doing things, so it's come. And if someone comes and do things differently.
Uh, from your routine or whatever it's yeah. Yes, in the younger you are the more. And then I don't know…Change when you are older is much more harder, but.

Interviewer
Yeah.

Participant
I guess this team everywhere, it's just. If, uh, your colleagues are not supported or supporting, or they are not, you know, flexible and it's harder because you already have the patients and their parents and everyone to deal with. On top of your colleagues or it's not….

Interviewer
And then there's one more thing that you said. If you can throw some light.. that if you try to change anything you were met with resistance is that from some experience.

Participant
Yeah, yeah. I mean, it's silly thing, but if you try to. Like I don't know, it did just learn is just absolutely thing OK, but and they were, we were just. You know the.. they have colours for a reason… Different colors because….anyway..

Interviewer
Don't worry.

Participant
Anyway. The guideline were changing because there are starting to say that if you put the high flow liquid in the distal…..but basically you needed to put certain liquids in in the in one colour of the IV line and other medication in the other colour. And I was trying to explain that because it was evidence based and I don't know… What we should be doing and you try to explain that to the other nurses and they get really rude to you.. And they say you are the band 6 Or band 7.. And I know better, but so it's…you know it's just. It's complicated when you are when you are telling that to someone that has more experience and you are...
So I yeah it, and they're saying that's what happened to me personally, and I think with everything that you want to do, it's more or less the same. It's, uh, it takes time to change things and….

Interviewer
Yeah. Okay I get it..Yeah alright, I think I have a covered we have covered most of the things.

I will stop this recording one second.

[Interviewer thanked the participant and discussed the next steps]