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Parents' lived experience of support through their neonate's end of life and grief journey: An interpretative phenomenology study

Michaela Barnard[a], Joanna Smith[b], and Tony Long[c]

[a]School of Health Sciences, Faculty of Biology, Medicine and Health, University of Manchester, Manchester, UK; [b]Sheffield Children's NHS Foundation Trust/School for Health and Social Care, College of Health & Wellbeing and Life Sciences, Sheffield Hallam University, Sheffield, UK; [c]School of Health and Society, University of Salford, Salford, UK

ABSTRACT

Medical and pharmacological advancements have influenced the ability to treat acutely ill neonates. However, complications of prematurity mean that death is unpreventable in some cases. The aim of this study was to explore parents' lived experiences of end of life care and their perceptions of support needs during and following the death of their baby in neonatal intensive care units in the United Kingdom. A qualitative interpretative phenomenological analysis design was adopted. Unstructured interviews were undertaken with seven parents (five mothers and two fathers). Interpretative phenomenological analysis was used to analyze the data. Four themes emerged from the analysis: 'the enormity of grief', 'redefining self and social relations', 'trying to survive' and 'routes to improved support'. Parents' experiences of neonatal care after the death of their baby were variable but all narratives highlight a grief that is deep and overwhelming. The Neonatal Grief Sandstorm visual tool, developed from the findings, has potential to support bereavement conversations between health professionals and parents.

Introduction and background

This article considers the connections between neonatal palliative and end of life events and parents' subsequent grief experiences, providing a future roadmap for care. The first month of life is the period when a child is most vulnerable, with a neonatal mortality rate in the United Kingdom (UK) of 1.53 per 1000 live births (MBRRACE-UK [Mothers and Babies Reducing Risk through Audit and Confidential Enquiries], 2022). The main causative factors for these deaths in developed and developing countries are preterm birth, intrapartum complications, infection and birth defects (World Health Organization, 2021).

Advances in medical and pharmacological technology have facilitated increased neonatal survival both for neonates on the edge of viability (23-24 weeks gestation) and for acutely ill babies up to term gestations (MBRRACE-UK, 2022). However, these advances do not ensure that all babies will survive past the neonatal period. The ability to sustain life in these situations can mean that while resuscitation and early stabilization is often possible, complications of prematurity, care and treatment mean that ultimately death may not be preventable. Central to a good quality neonatal service is effective care, support, and communication for the parents as well as the baby. This is of particular importance during palliative, end of life and bereavement phases of care. While most neonatal intensive care units (NICU) offer some form of bereavement interventions, there is wide variation in levels of bereavement care offered to families during and after a neonatal death. This variation in NICU bereavement interventions is replicated internationally as illustrated in a systematic review by Lakhani et al. (2024). Bereavement interventions in the UK range from the national standard of a single six-week appointment after death with the lead neonatal clinician, to regular support from a named bereavement nurse and/or bereavement counselor. The National Bereavement Care Pathway for Neonatal Death (National Bereavement Care Pathway, 2022) is a UK care pathway advocating for ongoing care including

CONTACT Michaela Barnard michaela.barnard@manchester.ac.uk School of Health Sciences, Faculty of Biology, Medicine and Health, University of Manchester, Jean McFarlane Building, Oxford Road, Manchester, M13 9PL, UK.

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emotional support for families. Hospital trusts and organizations within the UK are expected to adopt these standards, but the standards are not regulated.

Grief is a multifaceted and complex concept with an individualized experience. Grief theory is relevant to explain parents' experiences of grief in anticipation of and after the death of their baby and is considered in the discussion section of this paper. Similarly, there is merit in considering theories of attachment and separation in the journeys of grieving families because attachment, separation and loss are inexplicably linked in this context of care.

Neonatal staff are active facilitators in aiding attachment for parents who have sick babies and those babies in a palliative trajectory. Bowlby's foundational work from the late 1960s (available in an updated publication, Bowlby, 1997) in establishing infant and parental biological predisposition to make an attachment after birth empowers neonatal health professionals to support parents in making connections with their baby. Rubin (1976) developed Bowlby's work further by conceptualizing four interdependent tasks needed to establish successful attachment between mothers and babies from her work with mothers in the United States. Two of these necessary tasks ('binding-in' which is concerned with bonding, and 'learning to give of herself' which revolves around caregiving) are interrupted when a baby is acutely unwell and further heightened by separation through admission to the NICU. Fathers' experiences of attachment, while often deemed of lesser importance to those of mothers, has gained increasing recognition although there is a paucity of research in this area. A longitudinal study from Australia exploring the attachment experiences of first-time fathers, found that pregnancy is a significant time of attachment for fathers as well as mothers (Condon et al., 2013). Grief is potentially complicated for families experiencing neonatal death because attachment is first disrupted, and parents are then separated from the baby as the baby is transferred to NICU. This is further complicated with the tentative bonds of attachment broken to some degree by death.

The aim of this study was to explore parents' lived experiences and perceptions of support during and following the death of their baby. The research questions were:

1. What are parents' experiences during and following the death of their baby?
2. What impact does their baby's death have on parents' lives?
3. What support mechanisms helped parents to cope with the death of their baby?
4. What support strategies did parents need or desire during their baby's NICU admission and after the death?

The first author (MB) worked as a neonatal bereavement nurse in a UK tertiary NICU for several years, and therefore their skills of communication with grieving families were facilitative to this study's aim.

Method and materials

An interpretative phenomenological analysis (IPA) design was adopted, based on the processes associated with IPA developed by Smith (1994). This design is grounded in hermeneutics and Heideggerian phenomenology, which in turn originates from Husserl's phenomenological philosophical foundation (Heidegger, 2008). IPA was chosen because the methods facilitated the revealing of unique meaning and significance of the phenomenon by those experiencing it, which are then described and interpreted (Smith et al., 2009). A patient and public involvement (PPI) group of three parents was formed to co-construct and review study materials with a particular focus on sensitivity of wording and attracting fathers to the study.

Sample and participants

A purposive sampling strategy was used to recruit parents from two level three NICUs in the northwest of England. Level three units provide support to babies requiring intensive interventions. Pre-defined criteria are established before sampling in a purposive strategy. The aim is to select participants with experience of the phenomenon. Purposive sampling is the most common strategy in phenomenology, with the aim to facilitate a small group with rich lived experience (Frechette et al., 2020). Parents who were over the age of 16 when their baby died or received most of their care on a NICU were sought. Excluded from the study were parents who did not speak fluent English due to lack of funding for translation, and those whose baby was part of an ongoing coroner's inquest.

Clinical partners from the hospital trusts contacted the parents by post, with a letter and recruitment pack, when a minimum of six months had elapsed following their baby's death. The participant information sheet clearly stated the interviewer's experience in neonatal palliative and bereavement care to reassure parents that the interviewer would have insight into their recent experiences. Parents who wished to participate contacted MB by post, email or telephone,

and a subsequent phone contact was made to explain the study, answer questions, and arrange a place, date, and time for the interview if they wished to proceed.

Recruitment was difficult because of the context of the study: 116 deceased baby's parents were considered suitable for the study, 95 recruitment packs were sent out, and 21 parents were excluded for reasons of incomplete coroner's inquest or language difficulties. Nine parents responded, resulting in a response rate of 9.47%. Two parents decided not to proceed with the study. Seven parents aged 26-45 years participated in the study, including five mothers and two fathers, which included two couples. All parents were from white British ethnicity and were in heterosexual relationships, but they came from a diverse range of socio-economic backgrounds. The neonates whose parents participated in the study died from a range of causes (see Table 1). Recruitment was protracted as was anticipated when researching a difficult, sensitive, and emotive topic. Recruitment stopped for practical reasons including when ethical approval for the recruitment phase expired.

Ethics

Ethical considerations were prominent throughout the study because of the sensitivity required when approaching and collecting data from participants that have experienced a bereavement (Stroebe et al., 2003). A risk-based approach to assess, plan and strategize the ethical issues was used (Long & Johnson, 2007). Formal approval was obtained for the study from a regional National Health Service research ethics committee (reference: 14/NW1007). All standard ethical considerations of informed consent, data storage, confidentiality and anonymity were met according to the Health Research Authority (HRA) standards. The primary data were only available to MB and JS. Supportive strategies were planned to recognize and manage participants' emotions during data collection, while concurrently checking the desire to continue. Breaks and discontinuation of the interview were offered as needed. Verbal and written information about support mechanisms post-interview were offered to all participants at the end of the interview.

In addition, consideration was given to the psychological well-being of MB, the primary researcher, and strategies were implemented to reduce the psychological stress and potential risk of burnout from the emotive nature of the interviews, transcription and data emersion during analysis and writing. Strategies included monthly clinical supervision to manage the potential psychological burden of being the sole researcher collecting, transcribing, and analyzing data. A bereavement counselor provided clinical supervision.

Table 1. Causes of neonatal death ($n = 5$).

Cause of death	Numbers
Infection and Surfactant Deficient Lung Disease	1
Placental abruption leading to Hypoxic Ischemic Encephalopathy	1
Necrotising Enterocolitis	1
Exomphalus and suspected genetic abnormality	1
Antepartum hemorrhage leading to Hypoxic Ischemic Encephalopathy	1

Data collection

Data were collected using unstructured interviews, and a topic guide (Table 2) was used as a prompt as needed. Unstructured interviews were chosen so that parents' stories could be constructed in any format they wished. The first two interviews were 'pilot' interviews and following review of the transcripts and discussion with research supervisors, no changes were made to the topic guide. These interviews were included in the final data set. Parents were given a choice of where they wanted the interview to take place. One parent chose to be interviewed at the university where MB was based, and the remainder were interviewed in their home. The two mother-father couples chose to be interviewed together. The interviews were digitally

Table 2. Interview topic guide.

Warm-up - Could you tell me about yourself and your family?	
Questions	Prompts
1. Could you tell me about … (name)?	
2. Can you tell me about (name) and their time in hospital?	What helped you during this time? Did anything add to your difficulties during this time? On discharge, were you offered any ongoing support?
3. Could you explain how things have been for you since you left the hospital?	What have you struggled with? What has helped you? Have you been in touch with any support groups? Who do you talk to on a bad day?
Closure What would you recommend health care professionals could do to support a family in a similar situation?	

audio-recorded apart from one interview for which the parent preferred detailed notetaking.

MB undertook all of the interviews. Building trust and rapport was crucial to establishing an effective researcher-participant relationship quickly. All participants were previously unknown to the researcher undertaking the interview. MB's experience of building therapeutic relationships with bereaved parents was beneficial to establishing rapport. Consideration was given to Roger's core conditions of empathy, congruence and unconditional positive regard, which facilitated the promotion of disclosure on sensitive and emotive experiences (Rogers, 1957). Before the interview began, most parents wanted insights into the interviewer's experience as a parent generally and as a nurse in neonatal and bereavement care. A reciprocal exchange of basic information was offered. The warm-up question (Table 2) was used initially to promote discourse, and for some parents no further questions were required, only prompts and probes. When needed, a second question was used: 'Can you tell me about (*baby's name inserted)*?' From here, the story of their baby's life, end of life and the parent's bereavement journey unfolded, often in a non-linear way. The probing questions were used only if after sufficient time was allowed, the conversation had stalled. In reality, parents steered the direction of narrative with little prompting or probing. The interviews lasted from 60 minutes to three hours, with most interviews taking approximately 90 minutes. During the interview, fields notes were taken if needed. After each interview, initial reflective thoughts were noted in a journal. While data transcription was initially undertaken immediately after each interview, the researcher needed a one or two weeks' pause over time before undertaking transcription to aid coping with the emotional impact of the interview.

Data analysis

Data were analyzed using a six step IPA process (Smith et al., 2009). Transcription of the data included emotions such as crying or other audible emotions being noted at the relevant point. In IPA, data analysis steps one to four are idiographic and included reading, initial noting, developing emergent themes and searching for connections between emergent themes. It was only when these steps were complete for one transcript that the process was repeated for the next case (step five) and each case afterwards until all cases had been analyzed individually. Step six involved searching for patterns across the cases. A systematic process, and notes of decisions made, was adopted from transcription and throughout the six steps of data analysis to facilitate rigorous analysis.

Throughout the study, and when reporting findings, participants were referred to as parents, rather than participants, acknowledging their role in their baby's life, and reflecting the disenfranchized grief experienced in societal interactions and painful experience for parents bereaved in the neonatal period. Disenfranchisement can be defined as a conflict between the right to grieve as an individual sees fit and that of society's perception of this (Cassidy, 2023).

Rigor and trustworthiness

Establishing trustworthiness drew on the quality criteria proposed by Lincoln and Guba (1985). This included credibility, transferability, dependability, and confirmability. Trustworthiness was addressed by using a recognized research design, clear methodological description, strategies used to promote reliability in participant narratives, iterative questioning, thick description of the phenomena, frequent debriefing, peer scrutiny and a reflective commentary. Reflexivity, a component of confirmability, is essential in IPA research design but also because of the psychological burden the research context brought to the process. Transferability is recognized in the limitations section of this paper.

Rigor was facilitated by review of the analyzed transcripts by JS that furthered critical thought processes. Emergent themes were discussed with JS throughout the six step process and as they evolved into super-ordinate themes.

Findings

Four super-ordinate themes with subsequent sub-ordinate themes were developed to describe, understand and interpret parents' experiences of neonatal end of life and grief. The super-ordinate themes were the 'enormity of grief', 'redefining self and social relations', 'trying to survive' and 'routes to improved support' (Table 3). The findings culminated in the development of the Neonatal Grief Sandstorm visual tool that can be used by professionals with bereaved parents to facilitate discussion and support during parents' grief journeys. Excerpts from the transcripts are included to support each theme, though anonymized to maintain confidentiality.

Theme 1: the enormity of grief

The enormity of grief was a dominant feature across parent accounts regardless of whether death was a

Table 3. Super-ordinate and sub-ordinate themes.

Theme 1: The enormity of grief	Uncertainty
	Death realization
	Living through the event
	Life without their baby
	Forward journey
Theme 2: Redefining self and social relations	Redefining self
	Socially isolated
Theme 3: Trying to Survive	Sharing their baby's story
	Family, friend and peer support
	Professional support
Theme 4: Routes to improved support	Communicating clearly and with care
	Mapping appropriate support

planned withdrawal of care or an unexpected event. Parents expressed their grief to be beyond the imaginable expectation, shocking in nature, intrusive into every aspect of life, unmanageable and unfathomably vast.

> It's like you can't get over it because there's many little bits to it, it's too big. And I feel at this moment in time, I'm never going to be able to fully put a lid on it. It's one of them life-changing events in your life that, completely and utterly change everything you know as normal. Parent 5, Mother

Five sub-ordinate themes arose from common experiences shared by most parents and they related to 'uncertainty', the point of 'death realization' that their baby was dying, the experience of 'living through the event' of end of life, then 'life without their baby' and finally what emerging into a 'forward journey' felt like.

Uncertainty

Parents described either moments of or ongoing uncertainty over the facts and events that led to their baby's death. Uncertainty over prognosis, outcome and the issue of resuscitation added to parents' confusion about the events that occurred. Parents described going around in circles, as they tried to comprehend what had happened to their baby; this added to the enormity of their grief.

> We asked them to keep her alive, not withdraw care, didn't we? I don't think we understood at the time. Parent 3, Mother

Death realization

Parents' accounts revealed they eventually came a point of realization that their baby was going to die. For some, this realization was late and close to the actual time of death. The timing of this realization was an individual experience, often different to that of their partner. At times, realization came during in-depth discussion with a health professional about resuscitation. Other parents described a series of smaller events that ultimately resulted in them comprehending the reality that death was imminent and unpreventable.

> And it was in the morning that they started talking more about letting her go basically. And that's what we decided to do, well we didn't really decide… Parent 6, Mother

> We started to realize he wouldn't survive when they weren't able to say anything positive about him. I wanted someone to say something hopeful, but she couldn't because she didn't want to be dishonest. Parent 2, Mother

Living through the event

For most parents, the end of their baby's life was unbearable, emotionally painful, difficult to witness and sometimes traumatic. Parents described the slow moving of time, how each deterioration in their baby's condition brought a new rush of emotional pain, despair and helplessness. This phase of living through the event confirmed for some parents what they had already realized, that death was inevitable and irreversible.

> So, we were there all afternoon just watching the numbers get worse and worse and you knew, didn't you? At the time, you just wanted it to be over. Parent 7, Father

In these situations, some parents had not held their baby because they had been too unwell or if they had, those opportunities had been limited. Therefore, this was a precious time to hold, to love, to have the opportunity to bond with their baby and create memories. Parents appreciated the care they received after the death and that memory boxes were made together with the family and nursing staff.

> It wasn't feasible to hold her because of her condition. Afterwards we were able to hold her. Parent 4, Father

> We were grateful she was born alive because we had some days with her. Parent 3, Mother

Most of the parents described the death of their baby being a closed, intimate affair with just themselves, sometimes siblings and a nurse.

Life without their baby

The act of parents leaving their baby behind after death in the neonatal unit was a final severing of the living bond with their baby and this was the start of life without their baby. Parents spent a substantial time during the interviews describing their life, individual moments, and difficulties in the period since

their baby's death. For all parents, life without their baby had been inordinately painful. Across all the narratives, the first days and weeks after the baby's death were profoundly difficult. Some parents recalled feeling fractured, experiencing disordered thinking and an inability to function at a basic level. Time passed slowly and fast simultaneously for these parents and sometimes they lost days at a time without much memory. Some parents had caring responsibilities for siblings or other family members, which they described as an additional challenge at an already difficult time.

> You emerge from that clinical world, where day in day out, your life is ruled by the hospital and you're hoping for this great outcome and then suddenly…
>
> It feels like you have nothing to hope for again. Parents 7 & 6, Father & Mother

For many parents, there was a particular time in the early weeks/months of their grief that their life unraveled and a crisis point was reached. Some parents described mental and physical dysfunction with wide ranging symptoms. These crisis symptoms were evident to themselves, partners and family members. In some cases, parents revealed a partner or family member had intervened and sought help on their behalf. However, support did not always happen promptly or in the right format at this time of crisis.

> It's awful and I would be like, 'what's my name, what am I doing, where do I live?' Parent 5, Mother

Some parents explained adaptation to life gradually evolved where they continued to grieve but became accustomed to their baby not being with them. Those parents described adjusting to the loss but not feeling any less pain, they also described peaks in their grief related to situations or certain triggers.

Forward journey

In this sub-ordinate theme, parents conveyed a sense of longing for better times and improved psychological wellbeing but that moving forward did not mean leaving the past behind. In contrast however, one parent explained how difficult it was to hope for anything better and that despondency was their default position to life events.

> I think everyone's moved on now and it doesn't come up in conversation hardly at all now, does it? It's on the forefront of our minds the whole time. Parent 7, Father

Some parents revealed they were able to recognize that they could experience contentment when remembering times with their baby and the comfort of visiting their baby's grave. There were hopes expressed by some in relation to wanting to expand their families with another baby. The journey forward seemed an unpredictable and uncertain future.

Theme 2: Redefining self and social relations

The second super-ordinate theme related to the identity crisis parents experienced, as an individual, as a family unit and within society. While all parents were part of a couple relationship, they encountered personal isolation as their individual grief experiences followed different trajectories. Couples who were interviewed together also talked about a 'togetherness' in relation to negative encounters with other people. Equally, parents identified social exchanges with family and friends and occasionally health professionals that where hurtful because of insensitive comments. These exchanges left parents seeking the safety of an isolated existence for periods of time. The two sub-ordinate themes arising from the main theme were 'redefining self' and 'socially isolated'.

Redefining self

Parents described the sense of loss that occurred when they came home from the NICU after their baby's death. Homecoming was often sudden, and it left a profound gap in their sense of a support framework. Separation from NICU staff was felt to be jarring and difficult. Some parents expressed a sense of isolation from their partners at times, even though they were living together.

> There's no gelling between the NICU and where you go next. There's nothing. Parent 6. Mother
>
> I speak to my mum more than my partner. My partner is stressed with work. Parent 2, Mother

Some parents spoke about a crisis of identity having spent the pregnancy being mothers and fathers-to-be, but they were then left wondering if they were really parents. Sharing this experience appeared to be accompanied by a sense of inadequacy and some parents identified that talking about their feelings could result in an affirmation of parenthood. These conflicted feelings kept them from engaging with family and friends and some parents had experience of correcting professionals with regards to their role, as parent five asserted:

> I am her mum. Parent 5, Mother.

One mother talked about her experiences with her employer that left her feeling removed from her identity as a parent. She received a letter confirming

maternity pay, but there were no congratulations on the birth nor any condolences on her loss. When she raised this issue with her employer later, she received a reply that shocked her.

> Do you not think you should have sent a card or some flowers? And she said, 'well a lot of people go through this, you know.' Parent 1, Mother.

Socially isolated

Parents expected the gap in support that arose on leaving the NICU to be filled by friends and family. In some instances, this was the case, at least until the funeral, but eventually for most parents, that support ebbed away, leaving a sense of isolation.

> After a few weeks, everyone just disappears and you feel like, that's it now, I'm on my own. Parent 1

> I've lost so many friends, so many people that I spoke to for years just ignored me because they just didn't know what to say. They choose to pretend they don't see you; they walk another way. Parent 5, Mother

Navigating existing relationships proved to be inherently problematic as parents wanted to be surrounded by their close friends, but contact was sparse or did not occur at all. When parents actively sought a listening ear or comfort, friends were evasive or absent and they felt further distress, impacting the grief experience further.

Theme 3: Trying to survive

Parents described their experiences of the difficulty of coping with each day. Their ability to survive life after their baby's death, both physically and psychologically depended on their own actions and support from others. This super-ordinate theme had three subordinate themes of: 'sharing their baby's story', 'family, friend and peer support' and 'professional support'.

Sharing their baby's story

Unexpectedly, most parents wanted to share a picture of their baby during the interview, reiterating the need for their baby to be known. This desire to share their baby's photo confirmed their trust in the researcher-participant relationship. It was a privilege to see their baby and to be able to connect visually with this lived experience. Parents described the need to let people around them know who their baby was, that they had lived, died, and remained a part of their family. The collective narratives disclosed the strong parental need to reinforce the identity of their baby in the absence of their actual presence.

> Can I just show you a picture of her? I wear her on me (locket), that's the day of the funeral, I just feel it's very important to show you. Parent 5, Mother

Parents revealed a strong compulsion to talk about their baby and it appeared to be a coping mechanism that facilitated their grief. Parents felt like they could not help or control this need, especially in the early months post-bereavement. Parents described that they quickly developed an awareness of the discomfort in others when they talked about their baby. They highlighted various encounters where people would change the subject or suggest that parents needed to distract themselves from focusing on their baby.

> It's like a taboo subject. I find if I start mentioning, I can see them, 'oh God, please don't', because they don't know what to say. Parent 5, Mother

> I think we're quite open, we'd like to talk about it. Parent 6, Mother

Family, friend and peer support

Parental narratives described the family, friend and peer support mechanisms that were instrumental to their emotional wellbeing both in hospital with their baby but also afterwards in their grief journey. Family support seemed to have significant prominence for most parents, as they gathered around to offer comfort, support, and practical help. Not all parents experienced this cohesion with family however, for some, both close and wider family members became detached, difficult, and insensitive. Couples reflected on the support they provide to one another as they continue to navigate the days. Friendships prior to the bereavement often deteriorated but some parents did have positive experiences to share.

> We've had support from family and friends. On a bad day, we talk to each other. Parent 3, Mother

Many friendships had ceased abruptly or slowly disappeared. Most parents developed new and crucial connections with peers from a similar situation and this was the most helpful mechanism of support in their lives. Peer friendships and support were reciprocal and arose from a support group such as those organized by charities, or a remembrance event arranged by the hospital or NICU. Not all parents accessed peer support, but they had all considered it. The positive impact that peer support had on their lives was a reoccurring narrative.

> I would have done absolutely anything for another [bereaved] mother's number. I felt like no one in the world could ever understand what I had gone through

> but there's hundreds of women in the same situation. Parent 5, Mother

> I've made quite a few good friends through the group that I see all the time. It's nice to have someone you go to, to understand what you're feeling, and it has really helped me. Parent 1, Mother

Some mothers shared their worries about their partners unmet need for support. None of the fathers in the study had accessed peer support and one mother described the peer support group she attended was unsuitable for fathers.

> There needs to be something for fathers. My husband was not able to go in the day there were no evening and weekend sessions. He didn't find it helpful, mostly women went, and he didn't see the situation in the same light as the women did. My husband can't be the only one in this situation. Parent 2, Mother

> My partner finds it very difficult to talk to anyone about it. That's his way of dealing with it, he has gone into quite a depression. Parent 1, Mother

Professional support

Professional support came in different forms, access was difficult and it often had to be sought rather than offered. Each parent had experienced professional support in NICU, and most parents sought some form of professional support post-bereavement from either their general practitioner, a counselor, health visitor, the hospital where their baby died or a dedicated bereavement nurse. Parents revealed both supportive and unhelpful encounters with health professionals and it was through some of the negative encounters that their full experiences were revealed.

Some parents revealed negative interactions during their baby's life with midwives, doctors, and neonatal nurses. One parent described a comment after returning to her in-patient midwifery ward, where her family were waiting, as she needed a brief break from her baby's end of life period. The midwife's comments have stayed with her:

> Then one of the midwives said, 'oh what's going on here, a party?' And I thought, well that's a bit heartless. Parent 1, Mother

Parents reflected on the frustration and extreme anxiety that was provoked by differing opinions of doctors toward the end of life, with some expressing hopelessness while others concurrently advised parents to maintain hope. Conversely, parents had positive experiences of honest and empathetic communication during breaking bad news experiences from health professionals.

> What I do still find hard, you can speak to one doctor and then you could speak to another in the same day, you'll have one saying, 'there's not much more we can do' and then in the next breath you've got another saying, 'she just needs time'. Parent 5, Mother

> The consultants in our baby's care, I think they were very straight forward, weren't they? Yeah, they were very blunt. We didn't need flowery conversations. Parent 4, Father

> We're just still full of admiration for all the staff. Parent 6, Mother

Some parents had access to a bereavement nurse who visited them in their home; others did not, dependent on the area and where their baby died. Those that had access to this kind of in person support, found it helpful and those that didn't have access, wished they had this type of support.

> The bereavement nurse came, and she was by far the best person to speak to. But it was finished after 6 months. Parent 2, Mother

> I still see the bereavement nurse now and again, not as much obviously. I have so much to thank the bereavement nurse for." Parent 5, Mother

Theme 4: Routes to improved support

Exploring parents' experiences of support and asking them to postulate what would be helpful to future parents was a key objective of this study and informs this super-ordinate theme. During the interviews, most parents naturally progressed to discussing potential care improvements as they had an altruistic interest in future care for others. Parents knew what had been useful for them and what the shortfalls had been. The two sub-ordinate themes 'communicating clearly and with care', 'mapping appropriate support' represent the areas that were suggested for improvement.

Communicating clearly and with care

As discussed under the 'professional support' sub-theme, parents shared a range of communication experiences. The need for compassion was an experience raised across parents' accounts. Overwhelmingly, parents expressed concern at the late or urgent discussion of 'Do Not Attempt Cardio-Pulmonary Resuscitation' (DNACPR). Most parents didn't understand that any resuscitation attempt would not be curative of the preexisting conditions. None of the parents had experienced a preemptive DNACPR discussion ahead of time and therefore, they felt unprepared for engaging in a meaningful discussion; they

perceived the only answer they could give was to affirm resuscitation attempts. In retrospect, parents realized that often this was a futile attempt to revive their baby.

> There was one consultant and she might have known everything that was necessary to be known knowledge wise, but she had absolutely no empathy whatsoever. It was just a mechanical problem. Well, she really annoyed me, didn't she? Parent 4, Father

> And then they rang us just before midnight saying we're resuscitating her; you need to get here. They hadn't discussed resuscitation with us, only that phone call when we was on our way back. Parent 3, Mother

The issues of conflicting information outlined in the 'professional support' sub-ordinate theme further emphasizes the importance of how parents are communicated with. While information is important, the empathy and skills needed to convey that information is of equal importance. Parents expressed the need for compassionate communication that was consistent and realistic.

Mapping appropriate support

Mapping appropriate support started for most parents with expressing some of the negative experiences and envisaging how care could be conceptualized differently. Many parents shared experiences that related to returning to the NICU after the death of their baby and the distress this had caused them. Parents were asked to return to the NICU for reasons such as, picking up the death certificate, waiting to be escorted to the mortuary or the UK standard of a six-week consultant follow-up appointment. Parents described that returning to the NICU was a reluctant task, unacceptable and avoidable. Parents fervently articulated that once their baby had died, they did not want to return to the unit, which provoked strong and overwhelming emotions of dread, significant distress and these experiences potentially complicated the early grief processes.

> …and they made us go and wait on NICU again didn't they, for somebody to come down from the morgue to come and get us. Which, there was no need for us to go back on intensive care. That was days afterwards. Parent 4, Father

> The review appointment was helpful, but it had to happen on NICU. Parent 2, Mother

The collective parental narrative was to reframe the NICU experience from the current position of expecting parents to return if needed, to one where there is a definite end point. In addition, parents suggested that contact afterwards should take place in venues such as the outpatients department or a community clinic, away from the trauma of the memories associated with their baby's place of care and death.

Parents offered opinions about the support that could be offered for future families, including peer support and professional support. There were contrasting experiences after the baby's death, where some parents had received resourced support and others received none until they sought it out, often in desperation. Yet, all parents described the benefit or potential benefit of a bereavement nurse. Peer support mechanisms that parents recommended included charity support groups but also individualized support in the form of friendships with a parent who had also experienced a neonatal death.

> I would have liked a bereavement nurse because it took time before I even decided that I needed counselling and there was no one there to say to me, I think you need to talk to someone. Parent 1, Mother

Parents described wanting to be invested in aiding future services and they felt passionately that support should be easy to access, with a wide range of options available that would cater to the needs of the individual, inclusive of fathers. They made recommendations with regards to the timeliness of support.

> I think funding for bereavement support needs to extend past the 6 months. Six months feels like a second. If my support had ended there, I would have been in trouble. Parent 2, Mother

The four super-ordinate themes present parents lived experiences during their baby's end of life and their struggle with everyday life in the ongoing period after death. A visual tool has been developed from the data in this study.

Discussion

This study aimed to understand the lived experiences of parents during and following the death of their baby in a neonatal unit, with focus on the impacts on life afterwards. Further questions from this study related to what support aided parents' coping and function alongside other support that they desired but did not receive. The narrative accounts of end of life care presented through a parental lens offer a deeper insight for health professionals to understand the enormity of parents' grief experiences and the need to redefine themselves following the death of their baby (themes one and two). These themes resonate with preexisting literature from both a theoretical, paradigm and evidential perspective, but the final

themes 'trying to survive' and 'routes to future support' add to existing research by mapping the supportive strategies that aided parents who have lived through these difficult experiences. The development of the Neonatal Grief Sandstorm (NGS) tool arose from the data in all four themes and is presented later in this discussion.

Parents' end of life accounts conveyed distress and significant emotional pain, in particular, the raw and deeply personal experiences, around the time of their baby's death. Parents described their grief as an enormous entity, seemingly unending, uncontrollable and unfathomable. Multiple perspectives and paradigms have conceptualized the immediate experience of the death of a loved one and of being plunged into an encounter with grief (Bowlby, 1997; Klass et al., 1996; Stroebe & Schut, 1999). Most parents in a NICU context experience anticipatory grief, whether related to the missed normality in the arrival of their baby or to a deeper anxiety about survival. Klass et al. (1996) work with bereaved parents from the USA has useful application in a neonatal grief context in which continuing connections to the deceased baby have prominence. Klass rejects the idea that severing of bonds with the deceased is necessary for future function and acknowledges that the connection of a loved one can be sustained after the death. Klass et al. (1996) offer a debate on whether the grief experience is a case of broken hearts or broken bonds, and if there is the need to maintain connections with the dead person. Parents in this study expressed that their grief was not a 'hurt that could be mended', contrary to social constructs. Their grief centered on both a 'broken heart' and a 'broken bond', but it was the suddenness and, for some, the unexpectedness of both these aspects that was overwhelming.

Grief is often viewed inaccurately as a goal and solution-focused paradigm in which grief has an emotional intensity but an anticipated return to normal functionality with expedience is expected. This societal expectation does not reflect the experiences of parents in this study. They had a desire to retain ties to their deceased baby for the rest of their lives. Consequently, societal expectations for parents to be 'finished' with their grieving after an undefined acceptable point was a construct with which many parents struggled, resulting in a disenfranchized existence as they continued to grieve intensely beyond their friends' and families' expectations. The Stroebe and Schut (1999) Dual Processing Model (DPM) of grief that conceptualizes oscillation between a loss-orientation and a restoration-orientation experience has application to this study. The parents in this study appeared to reflect a loss-orientated position where grief and sadness intruded daily. However, most parents articulated a restoration-orientated perspective by sharing hope for the future.

While recognizing that only two participants were fathers, fathers' and mothers' descriptions of the enormity of their grief had similarities and differences, and these are reflected in the wider literature (Azeez et al., 2022; McNeil et al., 2021). Gender differences, mapped to the DPM of bereavement, suggest that men lean toward a restoration-orientated experience and that women lean toward a loss-orientated experience (Stroebe & Schut, 1999). However, there are unique factors related to the death of a neonate such as the expectations associated with becoming a parent, the intensity of human attachments and bonding with their baby, and the lack of opportunity to have tangible memories of their baby, which will influence the grief process. Fathers and mothers in this study appeared to describe their grief in similar ways but with different intensity at different times. Fathers, however, reported that the pressures of returning to work soon after the death of their baby meant that they felt unable to be immersed in their grief, compared to mothers. This suspension of fathers' grief work could potentially place them in a position of delayed psychological crisis. This delay in grieving can be exacerbated by mother-centric bereavement support groups that do not seem to meet the needs of fathers. The UK government introduced The Parental Bereavement (Leave and Pay) Act (2018), which can facilitate having the time to grieve, however, it offers only two weeks of minimal paid benefit and does not acknowledge the on-going and enduring grief that fathers experience (Azeez et al., 2022).

Parents' experiences of end of life care

Most of the parents' narratives presented a picture of inconsistency of care, particularly inadequate communication and conflicting information which hindered parents' ability to contribute to decisions about care. This was balanced with experiences of good communication. However, negative actions by health professionals, such as an insensitive communication styles that added to parental distress have been highlighted in previous research from Canada and Netherlands (Labrie et al., 2021; Lakhani et al., 2024;). Similarly, research from the United States has identified continuity in medical and nursing carer-circles, building a therapeutic relationship, informational continuity and consistency, and the transfer of information are essential to the quality of care provision (Machut et al., 2021). More widely, partnership

has been identified as a core element to family-centered neonatal care (Sigurdson et al., 2020).

Empathetic caring behaviors of health professionals such as ensuring interactions are genuine and sensitive in nature, always using the baby's name, and a compassionate approach to communication and daily care are valued by parents (Baughcum et al., 2017). Parents in this study emphasized a conversation that was particularly challenging related to resuscitation plans. Discussing resuscitation with the patient or next of kin is mandatory in the UK (Etheridge & Gatland, 2015). The timing and mode of information delivery in relation to DNACPR plans was not helpful. International studies have also highlighted the complexities of resuscitation conversations as part of a wider end of life discussion (Marlow et al., 2021). Parental dissatisfaction with breaking bad news experiences and a desire for a more compassionate approach was also found in Wege et al. (2023) German study. These results resonate with parents in this study who lacked understanding of the difference between 'Do Not Attempt Cardiopulmonary Resuscitation' and 'Allow Natural Death' and that resuscitation attempts would not be curative of the preexisting conditions. The issues of undertaking and optimum timing of these difficult conversations could be facilitated by better integration of perinatal advance care planning (PnACP). PnACP in the NICU has been associated with improved end of life care and parents' preparedness for their baby's death in a Canadian study by Lin et al. (2024). However, implementation of the PnACP in clinical settings remains variable according to a UK survey and further prioritization of this strategy is needed (Shaw et al., 2024).

Parents' experiences of bereavement

Being asked to return to the NICU for a death certificate or prior to a mortuary visit, provoked intensely traumatic responses in parents. The sights, sounds and smells of an environment associated with the death of their baby were overwhelming. The NICU parental experience should be reframed with a clear end point (when parents leave after the death). The culture of care should focus on supporting parents in their grief and facilitating reintegration of the family back into their community. These narratives highlight the need for understanding of the unique parental experiences of bereavement in the NICU as recognized in a Canadian systematic review by Lakhani et al. (2024).

Parents in this study lived with their partners, yet most described a pervading sense of loneliness. Mothers' and fathers' loneliness were derived from a need to protect their partner from the burden of their emotions, which led to the feeling of being alone in their grief. Parents' experiences of isolation share similarities with previous research. For example, Fernández-Sola et al. (2020) European study described the impacts of perinatal death on family dynamics and parents' social environments. Further, there are experiences of neonatal death that are unique to the mother such as physical reminders of pregnancy, labor, and lactation that were still present when they returned home, adding to feelings of isolation.

None of the parents in this study were referred for counseling by a health professional on leaving the NICU, although some parents were referred later in their grief journey. Timing of referral is subjective for each individual, but parents emphasized the need for referral to an experienced bereavement counselor. The evidence on use of or effectiveness of bereavement support interventions such as individual or group therapy for bereaved parents is insufficient as confirmed by a systematic review by Ainscough et al. (2022). Parents in this study accessed counseling after experiencing a crisis of being unable to cope, and they voiced the need for open and easier access to support. They perceived that a bereavement nurse would be able to detect a need for counseling and refer them before crisis was reached.

Wanting their babies to be known and remembered was at the heart of parents' stories. While they shared their own experiences and emotions, they were ever cognizant and sensitive to what their baby might have been experiencing during that difficult time. Dissemination of the stories in this paper will provide health professionals with an insight into the baby's end of life experiences. However, a pathway to facilitate the feedback of parents' stories to neonatal health professionals would be beneficial to ongoing care.

The neonatal grief sandstorm visual tool

The visual tool presented in Figure 1, draws on the themes that emerged from the analysis of parents' narratives and it aims to represent how parents survive the death of their baby and navigate life afterwards. The Neonatal Grief Sandstorm (NGS) represents three core areas of difficulty for parents who are grieving. 'Falling in' represents the distressing experience of emotional freefall when parents recognize the prognosis, palliation and/or death of their baby. The 'sandstorm' phase depicts parents' immersion in their grief, unable to see through or past the storm, experiencing fear and disorientation. 'On the ground' is a time where life ahead has some clarity and

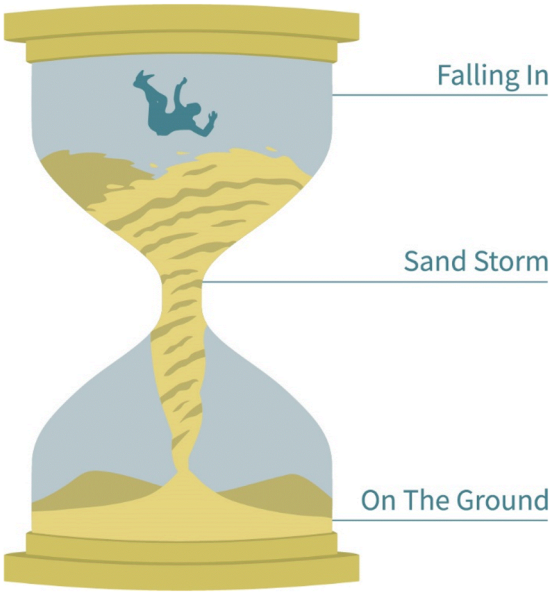

Figure 1. The neonatal grief sandstorm.

purpose. However, the journey can still be difficult to navigate and grief emotions are close to the surface.

The NGS reflects the non-linear and cyclical experiences that parents describe, where triggers occur in the form of a comment or a memory that throws them back into an acute grief experience. Then, the 'sand timer' inverts and the parent 'falls in' again and reeexperiences phases of their grief. The purpose of the tool is to provide a relatable way for both professionals and bereaved parents to visualize and discuss common experiences after the death of their baby. It is anticipated the tool could support bereavement care from a range of professionals and could be part of a 'toolkit' of resources when interacting with bereaved parents. Further research is needed to evaluate the usefulness of the NGS.

Implications for clinical practice, education, policy and research

Every interaction between a health professional and a parent whose baby is receiving palliative care matters. Conversations about palliative and end of life care have the potential to affect parents' grief experiences positively or negatively. These conversations should be part of a PnACP reflecting the need for careful planning and implementation.

Communication skills training including role play or simulation are crucial to facilitating compassionate and high quality experiences for families (Marlow et al., 2021; Randall et al., 2018). Health professionals need to recognize their own training needs and prioritize their development from foundational to advanced communication skills as appropriate. Hospital leaders and managers have a role in procuring and facilitating education and training that will benefit all service users of NICU and will impact positively on the experiences of grieving parents.

A resourced neonatal bereavement support service for all parents in UK is needed with a standard of provision met by all providers. The National Bereavement Care Pathway (2022) guides policy makers about what care provision is needed, but the current voluntary commitment to this care provision is inadequate. A strategic review and task team is needed to improve the quality of care at end of life related to continuity of care, resourcing and delivery of advanced communication skills training, the national strategy for PnACP including undertaking DNACPR conversations in the NICU setting.

Research about parents' experiences of neonatal palliative care remains in its infancy, however, there are some key priorities. The role and impact of resourced neonatal bereavement support services in improving parents' grief experiences using an existing validated grief assessment tool would further the existing evidence base. There is need for further exploration of siblings' and grandparents' experiences after the death of a brother/sister or grandchild through separate studies. Additionally, a study to implement and evaluate the NGS as a visual tool in understanding and planning for parents' support needs is needed.

Limitations

The key limitations of this study relate to sampling and recruitment. It was anticipated that recruitment would be difficult; asking parents to talk about this difficult event was unlikely to appeal to many parents in this situation. While small samples are desirable in phenomenology, the aim was to recruit 10 parents rather than seven. The response rate was low and a further strategy of recruitment through peer support groups did not yield any further participants. Additionally, only two fathers were recruited; optimally there would have been greater representation of gender. Most mothers requested the interview to be in the day, during the week, while siblings were at school and therefore, the majority of fathers were at work at that time. This does limit the transferability of findings to other settings and any conclusions about mother and father differences should be met with caution.

Conclusion

The parents' lived experiences during and following the death of their baby on a NICU reveals that there are both positive and negative experiences. Following

death, parents' grief is deep and overwhelming, and a range of supportive strategies are necessary to help parents to grieve in a healthy way. The Neonatal Grief Sandstorm visual tool is proposed to facilitate health professionals in their partnership work with parents to identify and authenticate parents' experiences and enable referral to other professionals when appropriate.

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ORCID

Michaela Barnard http://orcid.org/0000-0003-1646-1357
Joanna Smith http://orcid.org/0000-0003-0974-3591
Tony Long http://orcid.org/0000-0003-2726-8798

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