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Parental Experiences of Perinatal Loss with a Focus on Hospice Provision: A Thematic Analysis

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Article

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1 Introduction

Perinatal palliative care (PPC) is a specialised form of support provided to families of infants diagnosed with a life-limiting or life-threatening condition (Dombrecht et al. 2023). It is a comprehensive care approach aimed at enhancing the quality of life and ensuring comfort for a baby during the perinatal period (ACOG 2019), with families accepted onto the perinatal palliative care pathway from point of suspicion or diagnosis of a significant anomaly (Wilkinson et al. 2025). It is a holistic, family-focused model, aimed at providing emotional, psychological, and practical support to families, whilst ensuring comfort and dignity for the baby (Together for Short Lives 2017). While the perinatal period is typically defined as spanning from the 22nd week of gestation to seven completed days after birth (WHO, 2016), the timeframe for perinatal palliative care is more flexible, with some services extending support up to 18 months postnatally The heterogeneity documented in reviews of perinatal palliative care programs further implies that acceptable durations and models of care vary widely (Dombrecht et al., 2023). While some services limit their involvement to the antenatal and immediate postnatal period, others extend support well beyond infancy to address ongoing medical, emotional, and bereavement needs (Bertaud et al., 2023; Korzeniewska-Eksterowicz et al., 2025). This variation reflects differences in local service structures, referral pathways, and interpretations of what constitutes “perinatal” care. It also underscores the absence of a universally agreed timeframe for perinatal palliative care, highlighting the importance of flexible, family-centred approaches that adapt to individual circumstances and continuing needs. Perinatal Palliative care for babies is a specialised form of medical support for babies and emotional support to families when a baby is diagnosed during pregnancy, at birth or shortly after birth with a life-limiting or life-threatening condition or if there is uncertainty about survival or diagnosis. It focuses on improving quality of life and maximising the quality of the time families spend together if this time is potentially short by addressing physical comfort, emotional, social and spiritual needs. It promotes a multidisciplinary approach with shared decision making with parents, compassionate communication and co-ordinated care helping families create meaningful experiences with their baby whistle preparing for the potential for ongoing life, end of life care, death and bereavement support

Despite advances in perinatal care, infant mortality rates of approximately 5.8 deaths per 1,000 live births continue to be reported in high-income countries, with prematurity and chromosomal/congenital anomalies listed as the primary contributing factors (Callaghan et al. 2017; Mathews and Driscoll 2017). Whilst advances in perinatal care have improved neonatal outcomes, particularly for extremely preterm infants, only 20% of infants born at 22–24 weeks gestation survive without any neurodevelopmental impairment (Younge et al. 2017), highlighting the ongoing challenge of unfavourable diagnosis and poor prognoses. In response to these challenges, specialised perinatal palliative care has been steadily gaining recognition as a crucial support system for families navigating these difficult circumstances, playing a key role in addressing both the medical care of the baby and emotional needs of their families (Gomes Guimarães et al. 2018). However, in the United Kingdom (UK), the expansion of dedicated perinatal hospices and services remains limited and inconsistent, with gaps in the integration of maternity and palliative care services leading to regional variations in accessibility (Mitchell et al. 2021; Perinatal Hospice and Palliative Care 2021). While this study is situated in Northwest England, where hospice-based perinatal palliative care provision is relatively established, regional variation persists across the UK. Some regions have integrated perinatal palliative care within neonatal networks, whereas others have limited or no access to dedicated hospice services (Mitchell et al., 2021; Tatterton et al., 2023). Overall, perinatal palliative care continues to be delivered primarily within hospital maternity and neonatal units, with only limited specialist provision available through children’s hospices nationwide. (Tatterton et al. 2023). Despite the growing evidence of positive outcomes from engagement with hospice care(Boan Pion et al. 2021; Mitchell et al. 2021), provision and uptake remains low (Mendizabal-Espinosa and Price 2021). Barriers to referral include the common misconception that “palliative care” is solely associated with end-of-life care, as well as the wide range of conditions eligible for perinatal palliative support, from extreme prematurity to complex congenital anomalies. This can create uncertainty around when and for whom such care should be offered (Benini et al. 2020). This is further complicated by diagnostic uncertainty, which often results in hesitation among healthcare professionals to initiate discussions, consequently delaying critical support for families (Wool et al. 2016).

Further systemic barriers, including the absence of standardised referral pathways and limited interdisciplinary collaboration, hinder the seamless integration of perinatal palliative care into routine clinical practice (Dombrecht et al. 2023). While the need for timely referrals to specialist services is well recognised, with care pathways designed to foster continuity of care, relationship-building with professionals, and shared decision-making (Together for Short Lives 2017) the knowledge, experience, and confidence of healthcare professionals (HCPs) continue to influence the options presented to parents. Preconceived notions and varying levels of familiarity with perinatal palliative care contribute to inconsistencies in referral practices, ultimately leading to disparities in the experiences and care accessed by families (Peng et al. 2018; Wool 2013).

This paper seeks to explore the experiences of parents who have navigated a bereavement of their baby with support of perinatal hospice services, drawing insights from their personal narratives.

2 Methods

Qualitative data was collected via semi-structured interviews with parents who had experienced a perinatal death, to gain a deeper understanding of the complexities involved in caring for this cohort. All parents interviewed had received care from a palliative care team, as described in Appendix 1.

Sample and Recruitment

A total of 24 parents (12 couples) were approached. All had experienced a perinatal death over a two-year period between 2021 and 2023 and had received care from a hospice perinatal palliative care team. Parents who were identified as being vulnerable or experiencing complicated grief reactions were excluded by clinical staff prior to invitations being sent out. Purposive sampling was used to ensure representation of a broad spectrum of experience, including those who had been advised of problems relating to the pregnancy antenatally, those who had received a postnatal or postmortem diagnosis, and those who had delivered prematurely, resulting in the death of the baby. In addition, a sample of parents were included whose baby had died in utero, in hospital, or had been transferred to a children's hospice for end-of-life care. A total of 14 interviews were conducted, involving 17 parents and reflecting 12 pregnancies. In two cases, both parents participated separately in individual interviews, while three couples chose to be interviewed together. The remaining interviews were undertaken with either the mother or the father, depending on participant preference. Overall, the sample included six fathers and eleven mothers. To maintain participant anonymity, detailed demographic information has not been included. However, a brief description of the sample can be viewed in table 1 and 2 below.

Consistent patterns were identified within the first five interviews, with later interviews largely reinforcing previously observed findings rather than introducing novel perspectives. However, recruitment continued to ensure inclusion of both parents and differing care pathways. Ethical approval for the study was granted by HRA and Health and Care Research Wales REC reference: 22/YH/0028.

Data Collection

The interview schedule was devised by a small patient and public involvement group and trialled before data collection commenced. Semi-structured interviews were conducted either face to face (n=12) or online (n=2) by RL. Data was collected between July 2022 and July 2023. The interviews averaged 1 hour 20 minutes in length (range 55minutes – 2hours 10 minutes). A reflective diary was maintained by RL after each interview to provide further context.

Data Analysis

Opportunities for participants to verify the findings were provided throughout the analysis process. All interviews were recorded digitally, anonymised, and transcribed verbatim. Participants were also invited to review their transcripts. However, only two participants requested to do so. No changes were made to the original transcript following review.

Data analysis employed a reflexive thematic analysis approach (Braun and Clarke 2022). Each transcript was read by at least two authors (RL,RSL,KG), to facilitate data familiarisation. The authors (RSL, KG) then independently coded and generated initial themes. The analysis and evolving themes were discussed with the other authors (RL,FP,KW) to help develop analytical insights. Participants universally praised the support provided by the hospice, with many highlighting the compassion and professionalism of the clinical teams from the time of referral. For many, the hospice became a vital source of comfort, providing reassurance during an immensely challenging time. Following the death of their baby, activities such as fundraising and hospice promotion offered participants meaningful ways to remain connected, fostering a sense of purpose and ensuring their baby's memory lived on.

Reflexive thematic analysis was selected for its flexibility and suitability in exploring subjective experiences, acknowledging the active role of the researcher in meaning-making (Braun & Clarke, 2022). The six-phase approach guided the process: (1) data familiarisation, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report. This iterative framework enabled reflexivity, allowing the authors to continually revisit interpretations and ensure that themes evolved through collective discussion and analytic depth.

3 Findings

Five key themes were identified (Figure 1) relating to different points within their journey. (I) “the phrase that sticks” and (II) “why were we not offered this three weeks ago?” highlight the importance of HCP’s use of language and the timing of this communication when discussing the baby’s ill health, treatment, and their introduction to the concept of perinatal palliative care. (III) “everyone is different and [needs] something different” acknowledges that grief is a highly individual and non-linear process, with parents' subsequent support needs varying significantly. (IV) “common ground builds relationships” emphasises the connection or distance created in response to grief, and (V) “their names are going to be everywhere” stresses the importance of keeping their child’s memory alive. Exemplar quotes are provided in Table 3.

Theme 1: “The phrase that sticks”

Participants emphasised the profound impact of the language used by HCPs when discussing their baby’s condition and treatment plan. Insensitive or ambiguous terms, often perceived as overly clinical or medicalised, heightened feelings of uncertainty and distress (Q1.1,Q1.2). Conversely, clear, compassionate communication significantly alleviated anxiety and fostered trust in the care team (Q1.7,Q1.8).

In some cases, participants expressed frustration when they received conflicting or inadequate information or felt their concerns were dismissed by HCPs (Q1.3, Q1.4). This lack of clarity often prompted parents to seek additional information from external sources, including the internet, social media, or private healthcare providers (Q1.5). While these efforts sometimes enhanced understanding, they also risked undermining the parent-HCP relationship (Q1.6).

Theme 2: “Why were we not offered this three weeks ago?”

The timing and framing of communication about hospice services were pivotal in shaping parents’ experiences. Participants noted that language which normalised palliative care and emphasised its supportive role helped to reduce fear and stigma, enabling them to engage more openly (Q2.1). Many expressed a preference for earlier discussions about hospice care providing referrals were accompanied by clear explanations of the available services and their purpose (Q2.3, Q2.4).

Parents’ initial reactions to hospice referrals were often shaped by their pre-existing perceptions of hospice care (Q2.7). Those with inaccurate or incomplete understandings associated it with a sense of finality, resulting in more negative responses (Q2.2). Additionally, some participants felt that HCPs delayed referrals based on assumptions about how parents might react, further complicating their access to support (Q2.3). However, gentle introductions to hospice staff, such as informal ward visits, helped build familiarity and eased the transition into hospice care (Q2.4, Q2.5).

Theme 3: “Everyone’s different and [needs] something different”

Participants consistently highlighted the individual nature of grief, acknowledging that support needs varied greatly and evolved over time (Q3.1, Q3.2). Fathers often prioritised their partner’s wellbeing, as mothers faced both the physical and emotional challenges of pregnancy, birth, and loss. As a result, fathers were initially less likely to directly engage with hospice services but indirectly benefited from the support their partners received (Q3.3, Q3.4).

Participants also reflected on the varying experiences and needs of other bereaved parents. These differences sometimes created challenges in connecting with others whose circumstances differed, such as parents with living children finding it difficult to relate to those without, and vice versa (Q3.5, Q3.6).

Theme 4: “Common ground builds relationships”

Shared experiences of bereavement through baby loss created strong bonds among participants, with the hospice providing a safe and understanding environment where they could openly share their emotions and feel a sense of belonging (Q4.1, Q4.3, Q4.4). However, participants also described feelings of isolation stemming from a lack of understanding among family, friends, and colleagues (Q4.2,Q4.5,Q4.10). This disconnect arose from others' inability to fully empathise with the complexity of their grief.

Participants recognised that while family and friends were generally well-intentioned in their efforts to provide support, they often lacked the lived experience necessary to offer the same level of understanding as those who had undergone similar losses (Q4.6, Q4.7). Many participants reported that, despite these supportive efforts, loved ones occasionally struggled to articulate appropriate responses, sometimes making comments that were perceived as dismissive or unintentionally hurtful (Q4.7. This discrepancy in understanding underscored the distinct value of peer support networks and bereavement groups, which provided a more empathetic and validating space for emotional expression and coping (Q4.8 Q4.9).

Theme 5: "Their names are going to be everywhere" (Q5.8)

Preserving their baby's memory was a central priority for participants. Many emphasised the value of spending time with their baby in the calm, non-medicalised environment of the hospice, which helped strengthen their bond as a family (Q5.1, Q5.2).

Keepsakes such as hand and footprint jewellery were deeply cherished, with participants describing how these tangible items provided comfort and connection, (Q5.5. Q5.6), with many holding these items during the process of being interviewed. Acts of remembrance, such as fundraising and other memorial activities, allowed parents to honour their baby while contributing to the hospice's ongoing work (Q5.3, Q5.7). Participants also expressed a strong desire for others, including family and friends, to recognise their baby's personhood and remember them as an integral part of the family's story (Q5.8). Conversely, avoidance of acknowledging the baby was perceived as hurtful (Q5.4).

4 Discussion

This study explored the experiences of 17 parents who engaged with perinatal palliative care (PPC) in Northwest England. The findings underscore the importance of timely, empathetic communication, personalized support, and opportunities for shared connection and remembrance.

A consistent theme relates to the way in which PPC was framed and introduced. Many participants initially held limited or inaccurate understandings of PPC, often equating it solely with death or the discontinuation of medical care. This perception, rooted in societal discomfort and clinical ambiguity around the term “palliative,” contributed to initial resistance and anxiety (Saad et al. 2022). Framing perinatal palliative care as an extension of supportive antenatal care rather than solely an end-of-life intervention has been associated with improved parental engagement and service accessibility (Cote-Arsenault and Denney-Koelsch 2011).

Similarly, clinician hesitancy, uncertainty around prognosis, and concerns about overwhelming parents often contribute to delayed introductions of perinatal palliative care (Beltran and Hamel 2021; Wool and Catlin 2019). However, early, sensitively delivered discussions, tailored to parental readiness, can improve engagement and decision-making, ensuring families feel informed and supported from the point of diagnosis (Balaguer et al. 2012; Saad et al. 2022).

Delayed referrals have also been linked to missed opportunities for holistic care planning, limiting access to psychological, spiritual, and practical support when it may be most beneficial (Beltran and Hamel 2021) These experiences reflect broader challenges in PPC implementation, where clinician confidence and institutional norms vary widely risking inconsistent referral practices (Beltran and Hamel 2021)(Hardicre et al. 2021). Addressing these barriers requires a shift towards proactive communication strategies and structured referral pathways, integrating perinatal palliative care discussions into routine antenatal care and prioritising shared decision-making and parental autonomy (Silveira et al. 2023)

To address these gaps, systemic investment in workforce development is essential. Training programs should emphasize empathetic communication, trauma-informed care, and managing prognostic uncertainty(Beltran and Hamel 2021). This aligns with global best practices, which emphasise the importance of building parental trust, fostering early engagement, and enhancing preparedness for families navigating complex pregnancies (Saad et al. 2022; Wool and Catlin 2019). Additionally, incorporating the question “would I be surprised if this baby was to die in the perinatal period?” could help healthcare professionals identify families who may benefit and make appropriate, early referrals (Asenjo et al. 2025).

Creating standardised referral protocols, especially within antenatal care, can ensure that PPC is offered consistently and equitably, regardless of individual clinicians’ comfort levels. Integration of PPC into routine maternity services through shared care planning and multidisciplinary collaboration would further support early, seamless engagement with families (Tatterton et al. 2023). Several participants found that informal introductions to hospice teams, such as ward visits, helped normalize PPC and build trust. These gentle strategies allowed parents to engage at their own pace, reducing anxiety and stigma. International models also support phased introductions and peer-support initiatives to build confidence in PPC engagement (Hein et al. 2022).

The study also highlighted the emotional and social value of peer support and memory-making. Many parents formed deep emotional bonds through shared experiences of baby loss, particularly within the hospice setting. In contrast, participants described feelings of isolation from family, friends, and colleagues who lacked the lived experience to fully understand their grief. Peer networks offered a space for validation, empathy, and normalization of grief, helping parents feel less alone (Badenhorst and Hughes 2007; Zhuang et al. 2023). Involving the wider multi-generational family within hospice settings has been shown to strengthen support networks for bereaved parents, helping to challenge misconceptions about grief and encourage the continued presence of the baby in family traditions (Hein et al. 2022; Jackson et al. 2023). Increasing evidence highlights the value of family-inclusive grief support, particularly in cultures where perinatal loss is stigmatised or rarely acknowledged (Fernández-Sola et al. 2020). Global models of bereavement care increasingly recognise the significance of meaning-making practices, with studies demonstrating that rituals and community-driven remembrance events enhance emotional adjustment and reduce prolonged grief symptoms (Nyatanga 2020).

Preserving the baby’s memory was central to participants’ coping processes. Time spent in a calm, non-medical environment and access to memory-making opportunities such as keepsakes, photography, and symbolic rituals, reinforced their sense of parenting and connection. Acts of remembrance, including fundraising and advocacy, provided parents with a continued sense of purpose and identity. These practices align with bereavement models that emphasize meaning-making and continued bonds as vital for emotional recovery (Hart et al. 2022)(Anolak et al. 2019)

Previous research has demonstrated that parental experiences of perinatal loss are influenced by a range of demographic and clinical factors, including ethnicity, socioeconomic context, gestational age, and cause of death. Cultural norms and family expectations have been shown to shape how grief is expressed and supported (Fernández-Sola et al., 2020), while the timing and circumstances of loss can influence emotional adjustment and opportunities for memory-making (Zhuang et al., 2023; Jackson et al., 2023). These factors are likely to hold relevance for the current study cohort. However, further investigation is needed to understand how such demographic and clinical variations may impact experiences of and engagement with perinatal palliative care across diverse populations.

Recommendations

The study builds on previous research findings, adding to the body of knowledge and acknowledgement that further training and education is required for HCPs that work in neonatal and maternity services and are responsible for delivering bad news and introducing hospice services.

Efforts must be directed toward improving the integration of perinatal palliative care within maternity and neonatal care pathways. Currently, inconsistent service provision and gaps in accessibility reflect a need for systemic changes that prioritise equitable access to specialised PPC services across regions (Mitchell et al. 2021). Strengthening collaboration between hospital-based maternity services and hospice care providers is critical to creating a seamless care experience for families. Additionally, enhancing healthcare professionals’ knowledge and confidence in discussing PPC options through targeted training can reduce disparities in referral practices and ensure that families receive timely support. Implementing structured care pathways, such as those recommended by Together for Short Lives, could promote consistency, continuity of care, and shared decision-making, ultimately improving outcomes for bereaved families (Together for Short Lives 2017). These measures, combined with ongoing evaluation and feedback, would help address the variability in PPC delivery and better meet the emotional, practical, and psychological needs of families during perinatal loss.

Strengths and Limitations

The study's inclusion of both mothers and fathers provides a comprehensive understanding of parental experiences, capturing diverse perspectives that are often underrepresented in perinatal palliative care research. However, couples recruited were all "mother/father" and therefore the needs of same sex couples have not been explored. Reflexive thematic analysis of the transcripts was employed by two authors, one of whom has clinical experience in palliative care (KG) and one of whom was novel to the research area (RSL) to help reduce subjective bias.

5 Conclusion

This qualitative study explored the experiences of parents navigating perinatal loss with the support of perinatal palliative care services in the Northwest of England. The findings underscore the critical role of timely, sensitive communication, personalised support, and opportunities for memory-making in facilitating parents' journeys through grief. Parents highlighted the profound impact of language used by healthcare professionals, with clear, empathetic, consistent communication fostering trust and reducing distress. Delays in PPC referrals were a common concern, with participants expressing a preference for earlier engagement that could have allowed more meaningful time with their baby and smoother grief processing.

The study also emphasised the non-linear nature of grief and the need for flexible, individualised support, particularly for fathers, whose experiences are often under-addressed. It is unclear whether the shared experiences of baby loss within the hospice setting created valuable connections, while acts of remembrance and the opportunity to honour their baby provided parents with comfort and purpose.

To enhance the delivery of PPC, healthcare systems must prioritise training for professionals in empathetic communication, improve integration between maternity and palliative care services, and normalise discussions about PPC early in the care pathway. Expanding access to peer support and formalising opportunities for families to engage in memory-making could further support bereaved parents. By addressing these key areas, PPC services can better meet the emotional, psychological, and practical needs of families, ensuring compassionate care during an immensely difficult and emotionally complex time.

Collectively, these findings offer valuable insights for enhancing the equity and cultural sensitivity of perinatal palliative care and can inform the development of national strategies aimed at standardising referral pathways and strengthening support for bereaved families.

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7 Appendix 1

The Children's hospice intervention in this study involved early referrals, support at clinic appointments and scans, emotional support – someone for families to contact between appointments by phone, video call or face to face, separate antenatal classes run by a midwife, parallel birth planning – a concept where information is shared and documented about 'hoping for the best' but have a plan 'just in case of the worst' focusing on what would be important to a family and capturing wishes if time together as a family was going to be short whilst also incorporating some control into a birth plan with elements of a typical birth plan such as pain relief and positioning for birth. Antenatal memory making is encouraged with free bump photography and heartbeat recordings and there is support for the whole family with sibling support and complimentary therapies such as reflexology and reiki for both parents. Also support on the neonatal unit and in bereavement care if needed. For children who get home a baby drop in group is also available to families for peer support. Further information can be found at https://www.clairehouse.org.uk/

8 Introduction

Perinatal palliative care (PPC) is a specialised form of support provided to families of infants diagnosed with a life-limiting or life-threatening condition (Dombrecht et al. 2023). It is a comprehensive care approach aimed at enhancing the quality of life and ensuring comfort for a baby during the perinatal period (ACOG 2019), with families accepted onto the perinatal palliative care pathway from point of suspicion or diagnosis of a significant anomaly (Wilkinson et al. 2025). It is a holistic, family-focused model, aimed at providing emotional, psychological, and practical support to families, whilst ensuring comfort and dignity for the baby (Together for Short Lives 2017). Despite advances in perinatal care, infant mortality rates of approximately 5.8 deaths per 1,000 live births continue to be reported in high-income countries, with prematurity and chromosomal/congenital anomalies listed as the primary contributing factors (Callaghan et al. 2017; Mathews and Driscoll 2017). Whilst advances in perinatal care have improved neonatal outcomes, particularly for extremely preterm infants, only 20% of infants born at 22–24 weeks gestation survive without any neurodevelopmental impairment (Younge et al. 2017), highlighting the ongoing challenge of unfavourable diagnosis and poor prognoses. In response to these challenges, specialised perinatal palliative care has been steadily gaining recognition as a crucial support system for families navigating these difficult circumstances, playing a key role in addressing both the medical care of the baby and emotional needs of their families (Gomes Guimarães et al. 2018). However, in the United Kingdom (UK), the expansion of dedicated perinatal hospices and services remains limited and inconsistent, with gaps in the integration of maternity and palliative care services leading to regional variations in accessibility (Mitchell et al. 2021; Perinatal Hospice and Palliative Care 2021). At present, perinatal palliative care is predominantly provided by hospital maternity and neonatal units, with limited specialist provision offered in children's hospices, across the country (Tatterton et al. 2023). Despite the growing evidence of positive outcomes from engagement with hospice care(Boan Pion et al. 2021; Mitchell et al. 2021), provision and uptake remains low (Mendizabal-Espinosa and Price 2021). Barriers to referral include the common misconception that "palliative care" is solely associated with end-of-life care, as well as the wide range of conditions eligible for perinatal palliative support, from extreme prematurity to complex congenital anomalies. This can create uncertainty around when and for whom such care should be offered (Benini et al. 2020). This is further complicated by diagnostic uncertainty, which often results in hesitation among healthcare professionals to initiate discussions, consequently delaying critical support for families (Wool et al. 2016).

Further systemic barriers, including the absence of standardised referral pathways and limited interdisciplinary collaboration, hinder the seamless integration of perinatal palliative care into routine clinical practice (Dombrecht et al. 2023). While the need for timely referrals to specialist services is well recognised, with care pathways designed to foster continuity of care, relationship-building with professionals, and shared decision-making (Together for Short Lives 2017) the knowledge, experience, and confidence of healthcare professionals (HCPs) continue to influence the options presented to parents. Preconceived notions and varying levels of familiarity with perinatal palliative care contribute to inconsistencies in referral practices, ultimately leading to disparities in the experiences and care accessed by families (Peng et al. 2018; Wool 2013).

This paper seeks to explore the experiences of parents who have navigated a bereavement of their baby with support of perinatal hospice services, drawing insights from their personal narratives.

9 Methods

Qualitative data was collected via semi-structured interviews with parents who had experienced a perinatal death, to gain a deeper understanding of the complexities involved in caring for this cohort. All parents interviewed had received care from a palliative care team, as described in Appendix 1.

Sample and Recruitment

A total of 24 parents (12 couples) were approached. All had experienced a perinatal death over a two-year period between 2021 and 2023 and had received care from a hospice perinatal palliative care team. Parents who were identified as being vulnerable or experiencing complicated grief reactions were excluded by clinical staff prior to invitations being sent out. Purposive sampling was used to ensure representation of a broad spectrum of experience, including those who had been advised of problems relating to the pregnancy antenatally, those who had received a postnatal or postmortem diagnosis, and those who had delivered prematurely, resulting in the death of the baby. In addition, a sample of parents were included whose baby had died in utero, in hospital, or had been transferred to a children's hospice for end-of-life care. A total of 14 interviews were conducted, involving 17 parents and reflecting 12 pregnancies. In two cases, both parents participated separately in individual interviews, while three couples chose to be interviewed together. The remaining interviews were undertaken with either the mother or the father, depending on participant preference. Overall, the sample included six fathers and eleven mothers. To maintain participant anonymity, detailed demographic information has not been included. However, a brief description of the sample can be viewed in table 1 and 2 below.

Consistent patterns were identified within the first five interviews, with later interviews largely reinforcing previously observed findings rather than introducing novel perspectives. However, recruitment continued to ensure inclusion of both parents and differing care pathways. Ethical approval for the study was granted by HRA and Health and Care Research Wales REC reference: 22/YH/0028.

Data Collection

The interview schedule was devised by a small patient and public involvement group and trialled before data collection commenced. Semi-structured interviews were conducted either face to face (n=12) or online (n=2) by RL. Data was collected between July 2022 and July 2023. The interviews averaged 1 hour 20 minutes in length (range 55minutes – 2hours 10 minutes). A reflective diary was maintained by RL after each interview to provide further context.

Data Analysis

Opportunities for participants to verify the findings were provided throughout the analysis process. All interviews were recorded digitally, anonymised, and transcribed verbatim. Participants were also invited to review their transcripts. However, only two participants requested to do so. No changes were made to the original transcript following review.

Data analysis employed a reflexive thematic analysis approach (Braun and Clarke 2022). Each transcript was read by at least two authors (RL,RSL,KG), to facilitate data familiarisation. The authors (RSL, KG) then independently coded and generated initial themes. The analysis and evolving themes were discussed with the other authors (RL,FP,KW) to help develop analytical insights. Participants universally praised the support provided by the hospice, with many highlighting the compassion and professionalism of the clinical teams from the time of referral. For many, the hospice became a vital source of comfort, providing reassurance during an immensely challenging time. Following the death of their baby, activities such as fundraising and hospice promotion offered participants meaningful ways to remain connected, fostering a sense of purpose and ensuring their baby's memory lived on.

10 Findings

Five key themes were identified (Figure 1) relating to different points within their journey. (I) "the phrase that sticks" and (II) "why were we not offered this three weeks ago?" highlight the importance of HCP's use of language and the timing of this communication when discussing the baby's ill health, treatment, and their introduction to the concept of perinatal palliative care. (III) "everyone is different and [needs] something different” acknowledges that grief is a highly individual and non-linear process, with parents' subsequent support needs varying significantly. (IV) “common ground builds relationships” emphasises the connection or distance created in response to grief, and (V) “their names are going to be everywhere” stresses the importance of keeping their child’s memory alive. Exemplar quotes are provided in Table 3.

Theme 1: “The phrase that sticks”

Participants emphasised the profound impact of the language used by HCPs when discussing their baby’s condition and treatment plan. Insensitive or ambiguous terms, often perceived as overly clinical or medicalised, heightened feelings of uncertainty and distress (Q1.1,Q1.2). Conversely, clear, compassionate communication significantly alleviated anxiety and fostered trust in the care team (Q1.7,Q1.8).

In some cases, participants expressed frustration when they received conflicting or inadequate information or felt their concerns were dismissed by HCPs (Q1.3, Q1.4). This lack of clarity often prompted parents to seek additional information from external sources, including the internet, social media, or private healthcare providers (Q1.5). While these efforts sometimes enhanced understanding, they also risked undermining the parent-HCP relationship (Q1.6).

Theme 2: “Why were we not offered this three weeks ago?”

The timing and framing of communication about hospice services were pivotal in shaping parents’ experiences. Participants noted that language which normalised palliative care and emphasised its supportive role helped to reduce fear and stigma, enabling them to engage more openly (Q2.1). Many expressed a preference for earlier discussions about hospice care providing referrals were accompanied by clear explanations of the available services and their purpose (Q2.3, Q2.4).

Parents’ initial reactions to hospice referrals were often shaped by their pre-existing perceptions of hospice care (Q2.7). Those with inaccurate or incomplete understandings associated it with a sense of finality, resulting in more negative responses (Q2.2). Additionally, some participants felt that HCPs delayed referrals based on assumptions about how parents might react, further complicating their access to support (Q2.3). However, gentle introductions to hospice staff, such as informal ward visits, helped build familiarity and eased the transition into hospice care (Q2.4, Q2.5).

Theme 3: “Everyone’s different and [needs] something different”

Participants consistently highlighted the individual nature of grief, acknowledging that support needs varied greatly and evolved over time (Q3.1, Q3.2). Fathers often prioritised their partner’s wellbeing, as mothers faced both the physical and emotional challenges of pregnancy, birth, and loss. As a result, fathers were initially less likely to directly engage with hospice services but indirectly benefited from the support their partners received (Q3.3, Q3.4).

Participants also reflected on the varying experiences and needs of other bereaved parents. These differences sometimes created challenges in connecting with others whose circumstances differed, such as parents with living children finding it difficult to relate to those without, and vice versa (Q3.5, Q3.6).

Theme 4: “Common ground builds relationships”

Shared experiences of bereavement through baby loss created strong bonds among participants, with the hospice providing a safe and understanding environment where they could openly share their emotions and feel a sense of belonging (Q4.1, Q4.3, Q4.4). However, participants also described feelings of isolation stemming from a lack of understanding among family, friends, and colleagues (Q4.2,Q4.5,Q4.10). This disconnect arose from others’ inability to fully empathise with the complexity of their grief.

Participants recognised that while family and friends were generally well-intentioned in their efforts to provide support, they often lacked the lived experience necessary to offer the same level of understanding as those who had undergone similar losses (Q4.6, Q4.7). Many participants reported that, despite these supportive efforts, loved ones occasionally struggled to articulate appropriate responses, sometimes making comments that were perceived as dismissive or unintentionally hurtful (Q4.7. This discrepancy in understanding underscored the distinct value of peer support networks and bereavement groups, which provided a more empathetic and validating space for emotional expression and coping (Q4.8 Q4.9).

Theme 5: “Their names are going to be everywhere” (Q5.8)

Preserving their baby’s memory was a central priority for participants. Many emphasised the value of spending time with their baby in the calm, non-medicalised environment of the hospice, which helped strengthen their bond as a family (Q5.1, Q5.2).

Keepsakes such as hand and footprint jewellery were deeply cherished, with participants describing how these tangible items provided comfort and connection, (Q5.5. Q5.6), with many holding these items during the process of being interviewed. Acts of remembrance, such as fundraising and other memorial activities, allowed parents to honour their baby while contributing to the hospice’s ongoing work (Q5.3, Q5.7). Participants also expressed a strong desire for others, including family and friends, to recognise their baby’s personhood and remember them as an integral part of the family’s story (Q5.8). Conversely, avoidance of acknowledging the baby was perceived as hurtful (Q5.4).

11 Discussion

This study explored the experiences of 17 parents who engaged with perinatal palliative care (PPC) in Northwest England. The findings underscore the importance of timely, empathetic communication, personalized support, and opportunities for shared connection and remembrance.

A consistent theme relates to the way in which PPC was framed and introduced. Many participants initially held limited or inaccurate understandings of PPC, often equating it solely with death or the discontinuation of medical care. This perception, rooted in societal discomfort and clinical ambiguity around the term “palliative,” contributed to initial resistance and anxiety (Saad et al. 2022). Framing perinatal palliative care as an extension of supportive antenatal care rather than solely an end-of-life intervention has been associated with improved parental engagement and service accessibility (Cote-Arsenault and Denney-Koelsch 2011).

Similarly, clinician hesitancy, uncertainty around prognosis, and concerns about overwhelming parents often contribute to delayed introductions of perinatal palliative care (Beltran and Hamel 2021; Wool and Catlin 2019). However, early, sensitively delivered discussions, tailored to parental readiness, can improve engagement and decision-making, ensuring families feel informed and supported from the point of diagnosis (Balaguer et al. 2012; Saad et al. 2022).

Delayed referrals have also been linked to missed opportunities for holistic care planning, limiting access to psychological, spiritual, and practical support when it may be most beneficial (Beltran and Hamel 2021) These experiences reflect broader challenges in PPC implementation, where clinician confidence and institutional norms vary widely risking inconsistent referral practices (Beltran and Hamel 2021)(Hardicre et al. 2021). Addressing these barriers requires a shift towards proactive communication strategies and structured referral pathways, integrating perinatal palliative care discussions into routine antenatal care and prioritising shared decision-making and parental autonomy (Silveira et al. 2023)

To address these gaps, systemic investment in workforce development is essential. Training programs should emphasize empathetic communication, trauma-informed care, and managing prognostic uncertainty(Beltran and Hamel 2021). This aligns with global best practices, which emphasise the importance of building parental trust, fostering early engagement, and enhancing preparedness for families navigating complex pregnancies (Saad et al. 2022; Wool and Catlin 2019). Additionally, incorporating the question “would I be surprised if this baby was to die in the perinatal period?” could help healthcare professionals identify families who may benefit and make appropriate, early referrals (Asenjo et al. 2025).

Creating standardised referral protocols, especially within antenatal care, can ensure that PPC is offered consistently and equitably, regardless of individual clinicians’ comfort levels. Integration of PPC into routine maternity services through shared care planning and multidisciplinary collaboration would further support early, seamless engagement with families (Tatterton et al. 2023). Several participants found that informal introductions to hospice teams, such as ward visits, helped normalize PPC and build trust. These gentle strategies allowed parents to engage at their own pace, reducing anxiety and stigma. International models also support phased introductions and peer-support initiatives to build confidence in PPC engagement (Hein et al. 2022).

The study also highlighted the emotional and social value of peer support and memory-making. Many parents formed deep emotional bonds through shared experiences of baby loss, particularly within the hospice setting. In contrast, participants described feelings of isolation from family, friends, and colleagues who lacked the lived experience to fully understand their grief. Peer networks offered a space for validation, empathy, and normalization of grief, helping parents feel less alone (Badenhorst and Hughes 2007; Zhuang et al. 2023). Involving the wider multi-generational family within hospice settings has been shown to strengthen support networks for bereaved parents, helping to challenge misconceptions about grief and encourage the continued presence of the baby in family traditions (Hein et al. 2022; Jackson et al. 2023). Increasing evidence highlights the value of family-inclusive grief support, particularly in cultures where perinatal loss is stigmatised or rarely acknowledged (Fernández-Sola et al. 2020). Global models of bereavement care increasingly recognise the significance of meaning-making practices, with studies demonstrating that rituals and community-driven remembrance events enhance emotional adjustment and reduce prolonged grief symptoms (Nyatanga 2020).

Preserving the baby’s memory was central to participants’ coping processes. Time spent in a calm, non-medical environment and access to memory-making opportunities such as keepsakes, photography, and symbolic rituals, reinforced their sense of parenting and connection. Acts of remembrance, including fundraising and advocacy, provided parents with a continued sense of purpose and identity. These practices align with bereavement models that emphasize meaning-making and continued bonds as vital for emotional recovery (Hart et al. 2022)(Anolak et al. 2019)

Recommendations

The study builds on previous research findings, adding to the body of knowledge and acknowledgement that further training and education is required for HCPs that work in neonatal and maternity services and are responsible for delivering bad news and introducing hospice services.

Efforts must be directed toward improving the integration of perinatal palliative care within maternity and neonatal care pathways. Currently, inconsistent service provision and gaps in accessibility reflect a need for systemic changes that prioritise equitable access to specialised PPC services across regions (Mitchell et al. 2021). Strengthening collaboration between hospital-based maternity services and hospice care providers is critical to creating a seamless care experience for families. Additionally, enhancing healthcare professionals' knowledge and confidence in discussing PPC options through targeted training can reduce disparities in referral practices and ensure that families receive timely support. Implementing structured care pathways, such as those recommended by Together for Short Lives, could promote consistency, continuity of care, and shared decision-making, ultimately improving outcomes for bereaved families (Together for Short Lives 2017). These measures, combined with ongoing evaluation and feedback, would help address the variability in PPC delivery and better meet the emotional, practical, and psychological needs of families during perinatal loss.

Strengths and Limitations

The study's inclusion of both mothers and fathers provides a comprehensive understanding of parental experiences, capturing diverse perspectives that are often underrepresented in perinatal palliative care research. However, couples recruited were all "mother/father" and therefore the needs of same sex couples have not been explored. Thematic analysis of the transcripts was employed by two authors, one of whom has clinical experience in palliative care (KG) and one of whom was novel to the research area (RSL) to help reduce subjective bias.

12 Conclusion

This qualitative study explored the experiences of parents navigating perinatal loss with the support of perinatal palliative care services in the Northwest of England. The findings underscore the critical role of timely, sensitive communication, personalised support, and opportunities for memory-making in facilitating parents' journeys through grief. Parents highlighted the profound impact of language used by healthcare professionals, with clear, empathetic, consistent communication fostering trust and reducing distress. Delays in PPC referrals were a common concern, with participants expressing a preference for earlier engagement that could have allowed more meaningful time with their baby and smoother grief processing.

The study also emphasised the non-linear nature of grief and the need for flexible, individualised support, particularly for fathers, whose experiences are often under-addressed. It is unclear whether the shared experiences of baby loss within the hospice setting created valuable connections, while acts of remembrance and the opportunity to honour their baby provided parents with comfort and purpose.

To enhance the delivery of PPC, healthcare systems must prioritise training for professionals in empathetic communication, improve integration between maternity and palliative care services, and normalise discussions about PPC early in the care pathway. Expanding access to peer support and formalising opportunities for families to engage in memory-making could further support bereaved parents. By addressing these key areas, PPC services can better meet the emotional, psychological, and practical needs of families, ensuring compassionate care during an immensely difficult and emotionally complex time.

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Obstetrics Gynecol **134**

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14 Appendix 1

The Children's hospice intervention in this study involved early referrals, support at clinic appointments and scans, emotional support – someone for families to contact between appointments by phone, video call or face to face, separate antenatal classes run by a midwife, parallel birth planning – a concept where information is shared and documented about 'hoping for the best' but have a plan 'just in case of the worst' focusing on what would be important to a family and capturing wishes if time together as a family was going to be short whilst also incorporating some control into a birth plan with elements of a typical birth plan such as pain relief and positioning for birth. Antenatal memory making is encouraged with free bump photography and heartbeat recordings and there is support for the whole family with sibling support and complimentary therapies such as reflexology and reiki for both parents. Also support on the neonatal unit and in bereavement care if needed. For children who get home a baby drop in group is also available to families for peer support. Further information can be found at https://www.clairehouse.org.uk/

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