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The role of children's hospices in perinatal palliative care and advance care planning: The results of a national British survey

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Abstract

Introduction: Perinatal palliative care services are increasingly available globally, offering a range of clinical and psychological support services to families during pregnancy, in the neonatal period and following the death of a baby with a life-limiting or life-threatening condition. Little is understood about the role of children's hospice care and how it contributes to effective perinatal palliative care.

Design: The study aims to answer the question "what is the role of children's hospices in the provision of perinatal palliative care and advance care planning in the United Kingdom?"

Methods: An electronic survey was sent to all 54 children's hospices in the United Kingdom between May and June 2022.

Results: Thirty hospices responded, representing 54% of the sector. All regions of all four counties are represented. Numbers of referrals to hospices for perinatal palliative care have increased significantly over the last 5 years. Hospices provide a range of services for families and babies, usually from the point of diagnosis or recognition of a life-limiting or life-threatening condition, underpinned with counseling and emotional support. Hospices worked with a range of professionals and services, most commonly fetal medicine and neonatal services. Advance care plans were an important element of effective perinatal palliative care, strengthening parent–professional and interprofessional relationships.

Conclusion: Children's hospice services play an important and growing role in the perinatal care of babies and families following the diagnosis or recognition of a life-limiting or life-threatening condition. The family-centered approach to care, from a broad, biopsychosocial perspective means that hospices make a unique and meaningful contribution to both the clinical and psychological needs of families.

Clinical relevance: The family-centered approach to care, from a broad, biopsychosocial perspective means that hospices make an important contribution to both the clinical needs of babies, and psychological needs of families antenatally, in the neonatal period and after death.

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KEYWORDS
advance care planning, family-centered care, fetal medicine, hospice, neonatology, palliative care, prenatal diagnosis

INTRODUCTION AND BACKGROUND

Perinatal palliative care is increasingly available around the world, offering families psychological and emotional care and support, as well as supporting the clinical needs of babies, should pregnancies result in live birth. Congenital malformations, deformations, and chromosomal abnormalities (International Classification of Diseases [ICD-10] codes Q00–Q99) are the leading cause of infant death in many developed countries around the world including Australia (Australian Institute of Health and Welfare, 2021), Canada (Statistics Canada, 2022), China (Yang et al., 2020), England and Wales (Office for National Statistics, 2022), the European Union (Onambele et al., 2019), Israel (Kasirer et al., 2018), and the United States of America (Kingsmore et al., 2020).

Advances in antenatal care and technology around diagnostic testing during pregnancy have led to an increase in the frequency of life-limiting fetal diagnoses and the detection of anatomical congenital anomalies. Ultrasound scans in pregnancy are generally viewed by parents as a social event, where they can connect with their baby, as well as an opportunity for reassurance (Lalor et al., 2008; Øyen & Aune, 2016). Technological and screening advancements have led to earlier diagnosis of life-limiting or life-threatening conditions (LLLTCs) antenatally (Power et al., 2018). Parents are often unprepared for adverse findings, leaving them feeling intense grief and sadness when a LLLTC is identified (Benute et al., 2012). This can be further compounded by professionals' inexperience and lack of confidence in explaining findings in a sensitive manner, due to the continued uncertainty around prognosis (Lalor et al., 2007; Power et al., 2018). Parents have reported the initial distress of diagnosis can be reduced when transparent, empathetic, and timely information is communicated to them (Branchett & Stretton, 2012; Fleming et al., 2016). It is important that parents are supported in making informed decisions about whether to electively terminate the pregnancy, attempt fetal intervention, or whether to commence on a palliative care pathway (Hodgson et al., 2016; Kratovil & Julion, 2017).

Parents who choose to continue with their pregnancy after a diagnosis of a LLLTC have been found to benefit from early palliative care (Hancock et al., 2018). Perinatal palliative care offers a holistic approach to holding, guiding, and supporting babies and their families after a LLLTC has been identified (Together for Short Lives, 2022). Early palliative care gives parents the power to make informed decisions, the platform to access therapeutic support, and the space to plan care which acknowledges and honors the baby's life, however, long or short (Cortezzo et al., 2020; Lord et al., 2022). Parents strongly value empathetic communication, having a sense of control, being validated and having the time to love and make memories with their baby (Thornton et al., 2021).

Although there are well established principles of perinatal palliative care, and the benefits for families and babies are well documented, practice remains fragmented and inconsistent (Boan Pion et al., 2021). In the United Kingdom (UK), it is suggested there are 2109 neonates who die per year who would benefit from palliative care (Bliss and Together for Short Lives, 2012), of which 98% die in the hospital setting (Together for Short Lives, 2022). There are 54 children's hospices in the UK. These are independent, charitable organizations that offer a range of family centered, palliative care services to babies, children and adolescents and their families, in hospice buildings, the community setting (Tatterton, 2019), or by delivering services in hospitals. Palliative care services include short breaks, symptom management, end of life care and bereavement support before and after the death of a baby or child (Tatterton et al., 2021). Despite 93% of neonatal units having access to hospice support, only 63% refer to hospice services (Price & Mendizabal-Espinosa, 2019). Complex challenges have been identified previously around hospice staff's experiences of providing palliative care for infants referred from the hospital, including an "us and them" culture, hospitals holding onto patients due to lack of education about hospice services, and staff feeling that parents wanted their babies to be kept in the hospital environment (Price & Mendizabal-Espinosa, 2019).

LITERATURE REVIEW

A comprehensive search of the international literature around perinatal palliative care found a dearth of research around the role of children's hospices and perinatal palliative care. Much of the literature focuses on the experience and services offered by neonatologists (Cortezzo et al., 2013), pediatricians and maternal fetal medicine doctors (Cortezzo et al., 2019), interdisciplinary perinatal palliative care teams based in the hospital (Doherty et al., 2021; Tucker et al., 2021; Wool, 2015; Wool et al., 2016), and neonatal units (Cerratti et al., 2020; Cortezzo et al., 2013; Niehaus et al., 2020). Although palliative care services are offered and valued by staff (Cerratti et al., 2020; Cortezzo et al., 2013: Niehaus et al., 2020) there is variability around when this service is offered to families, with some providing services antenatally, from diagnosis and others providing care postnatally.

It is widely accepted that early palliative care can have a positive impact on the experience of families (Cerratti et al., 2020; Cortezzo et al., 2013; Niehaus et al., 2020) and their bereavement outcomes (Wool & Catlin, 2019). Although most studies found that staff felt prepared for, and enabled to care for neonates with LLLTCs, (Cerratti et al., 2020; Cortezzo et al., 2013, 2019; Niehaus et al., 2020; Tucker et al., 2021), some studies highlighted limited palliative care provision for infants, or suggested the needs of babies with LLLTC were not being addressed (Cortezzo et al., 2013; Williams-Reade et al., 2015). Some staff expressed the unique complications around neonatal palliative

care being offered at the beginning of life and although the majority knew palliative care could be offered early, generally this did not occur:

> …there are definitely some things associated with palliative care that could be started right after the time of diagnosis, or right after the time of birth […] But I think, typically, the majority of it is focused at […] the end of life, when that is closer in sight.
>
> (Williams-Reade et al., 2015, p. 181)

There is disparity in the confidence of professionals providing palliative care, with many practitioners not having additional training in how to support families of babies with LLLCTs (Cerratti et al., 2020; Cortezzo et al., 2013; Niehaus et al., 2020; Williams-Reade et al., 2015; Wool, 2015; Wool et al., 2016). A lack of policy and guidance within units to assist in the delivery of palliative care was highlighted (Cerratti et al., 2020; Williams-Reade et al., 2015; Wool et al., 2016). Variation in the communication, views, expectations, and practice of professionals around palliative care was also evident (Cerratti et al., 2020; Cortezzo et al., 2013, 2019; Doherty et al., 2021; Niehaus et al., 2020; Wool, 2015; Wool et al., 2016). Tucker et al. (2021) found that perinatal palliative care pathways increased communication and trust between professionals.

Advance care plans and birth plans were also seen to enhance communication between the family and members of the multidisciplinary team (Cortezzo et al., 2019; Tucker et al., 2021; Wool et al., 2016), as well as a way of supporting parents in making decisions around comfort care rather than intensive medical treatment (Doherty et al., 2021; Wool et al., 2016). Wool et al. (2016) found that nearly all programs in their survey of perinatal palliative care service in the United States (US) offered advance care planning (ACP). Despite this, and the broad acknowledgement of the benefits of ACP in children's palliative care (Cortezzo et al., 2019; Niehaus et al., 2020; Tucker et al., 2021; Wool, 2015; Wool et al., 2016), the studies based in neonatal units did not discuss advance care plans.

In the UK, there has been growing interest and investment in the provision of perinatal palliative care over the last 13 years, with charities such as Together for Short Lives and Bliss developing pathways (Bliss and Together for Short Lives, 2012) and policies to support the planning and delivery of palliative care to babies and their families. Children's hospices are the dominant provider of children's palliative care in the UK (Tatterton, 2019; Taylor & Aldridge, 2017). Currently, the role of hospices in the planning and delivery of perinatal palliative care is unclear. To date, there are no studies that explore this important aspect of palliative care for babies, children and young people, and their families.

METHODS

Aim

The aim of this study was to explore the role of children's hospices in the planning and provision of perinatal palliative care and advance care planning in the UK, and to ascertain the approaches taken by organizations to meet the needs of babies and their families. This was achieved by answering the research question "what is the role of children's hospices in the provision of perinatal palliative care and advance care planning in the United Kingdom?"

Study design, setting, and sampling

An online survey was developed to explore the prevalence of support available to families perinatally, and the roles that hospices played in delivering that support. The role of hospices in perinatal advance care planning, the professions hospices work with, and the services offered to neonates and their families in hospices and the community setting were of particular interest.

All 54 children's hospices in the UK were invited to participate, regardless of their involvement in perinatal palliative care. The survey was sent to the education leads, directors of nursing and chief executives of children's hospices via email and administered online using Jisc Online Surveys.

Data collection

A 24-point survey, comprising open and closed questions, was designed to identify the ways in which hospices support families perinatally by exploring the services offered in pregnancy, around the time of birth and postnatally. In addition, the survey sought to identify key working relationships in the planning and delivery of perinatal palliative care, and the role hospices take in ACP. Several steps were taken to ensure the validity and reliability of the survey. The survey was drafted by MT, and amended by all authors, in consultation with healthcare professionals and parent representatives, ensuring content validity. To examine reliability, a pilot survey was conducted by hospice professionals in the Yorkshire and Humber Children's Palliative Care Network in the North of England. This included multiple professionals from the same hospice completing the survey, allowing inter-rater reliability to be assessed. Consistent responses were given by practitioners based in the same organization, indicating inter-rater reliability. Cohen's kappa was used to determine inter-rater reliability; 100% agreement between 'raters' (i.e., those completing the survey) was identified, resulting in a kappa of 0.97, suggesting 'almost perfect' alignment (McHugh, 2012). Feedback from the pilot was used to modify the survey, before being sent out for completion.

Data analysis

Due to the relatively small dataset, quantitative data were anonymized and collated using a Microsoft Excel spreadsheet by MT. Qualitative, free text comments were analyzed using deductive content analysis (Elo et al., 2014). These were coded independently by MT and MF, and discussed and agreed by HS and CW. Selected quotes were used to add depth to the quantitative findings.

FINDINGS

Thirty children's hospices from across all four countries of the UK responded to the survey in May and June 2022. This represents 54% of British hospice services for children including services provided in all seven National Health Service (NHS) regions of England, and the whole of Northern Ireland, Scotland, and Wales.

Children's hospices and perinatal palliative care

The number of referrals received by children's hospices for perinatal palliative care is increasing. Most hospices that responded did not collect specific data on the number of perinatal referrals. Of the 12 services that provided data, referrals varied significantly across organizations. Increases in referrals over the last 5 years were seen in nearly all of those who provided data (Figure 1), showing numbers from individual services and the cumulative total.

The services offered to families vary (Figures 2 and 3), which demonstrate that more hospice-based care services are available (Figure 2) than those offered in family homes (Figure 3). All hospices suggested that care after the death of a baby, including the provision of bereavement support to family members was offered.

There appears to be growing interest in broadening referral criteria to meet the needs of families in the perinatal period across hospices, with 20% ($n = 6$) of organizations highlighting pilots or planning to increase the support available to families. These include the provision of neonatal palliative care:

> 'We are working towards community based short breaks for a defined number of sessions where there is a defined need.'
>
> (hospice 14)

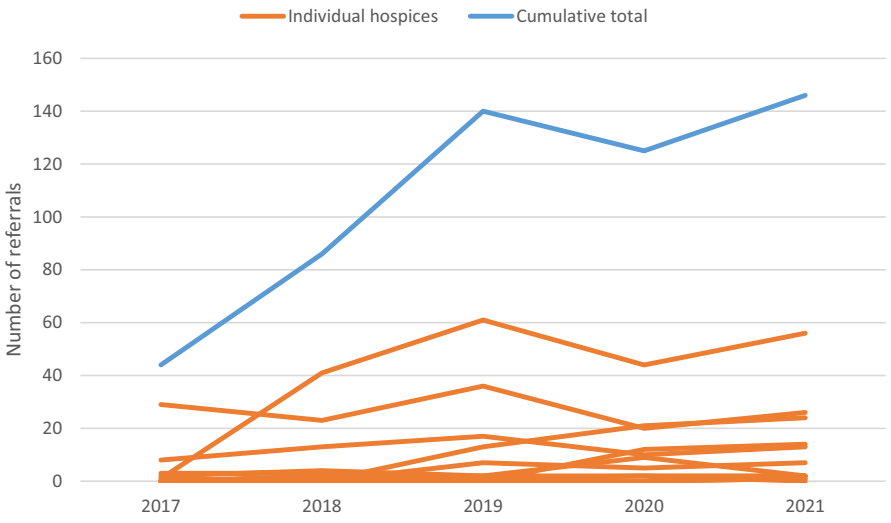

FIGURE 1 Perinatal referrals received by hospices between 2017 and 2021.

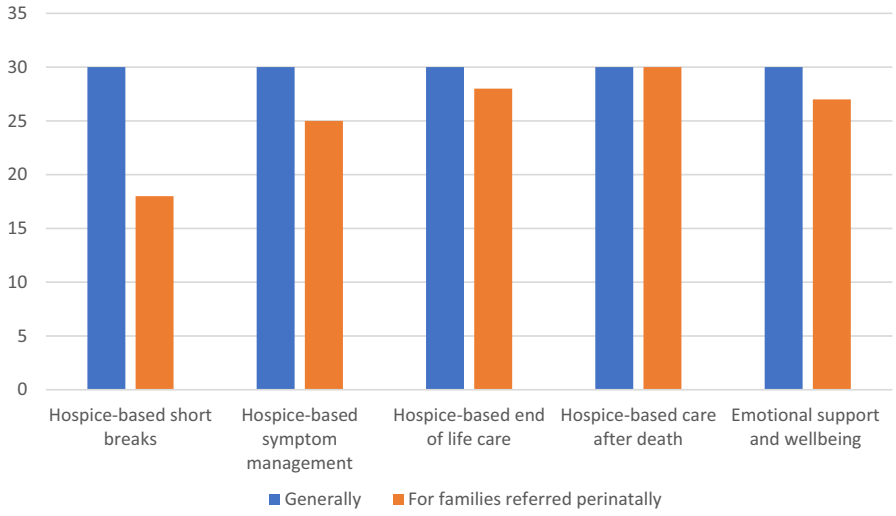

FIGURE 2 Hospice-based children's hospice services and emotional support.

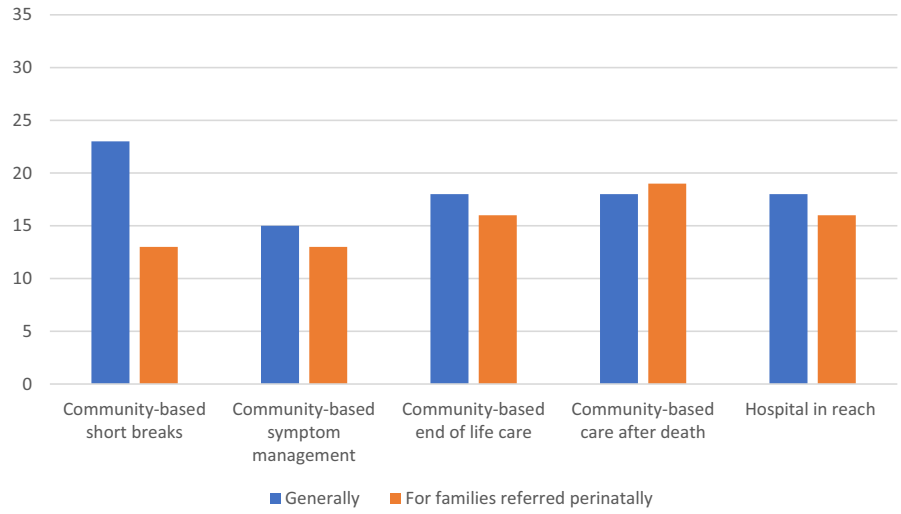

FIGURE 3 Community-based children's hospice services for children.

And care of babies after death:

> 'We are currently working on a pilot project supporting families to take babies home when they have died prior to or soon after birth.'
>
> (hospice 2)

Most hospices had clear referral criteria for perinatal referrals, using the Together for Short Lives neonatal pathway (Dickson, 2019) or the 2010 British Association of Perinatal Medicine (2010) guidelines to inform decisions. Variation was seen in the gestational age of acceptance for referrals. Forty-three percent ($n = 13$) of services reported to accept referrals from the point of diagnosis or reignition of a life-limiting or life-threatening condition. Some hospices had gestational age restrictions in place, which varied between 12 and 24 weeks. (Figure 4).

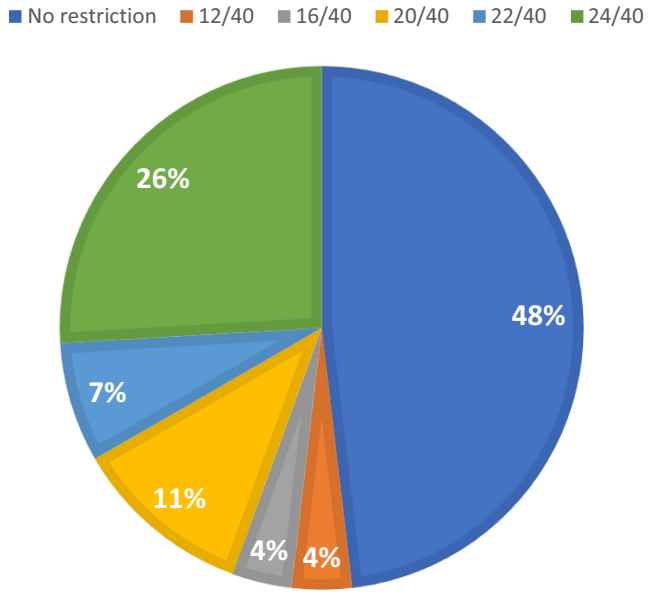

FIGURE 4 Gestational age of acceptance by children's hospices.

TABLE 1 Perinatal bereavement support offers by participating children's hospices

Gestational age	Number of hospices
Counseling/emotional support during pregnancy	80% ($n = 24$)
Bereavement support, if baby dies in utero before 24 weeks gestation	63% ($n = 19$)
Bereavement support, if baby dies in utero after 24 weeks gestation	77% ($n = 23$)

Antenatal care

Counseling and emotional support were offered to families by 80% ($n = 24$) of children's hospitals who responded to the survey. Fifty-seven percent ($n = 17$) of hospices accompanied parents to antenatal appointments, including scans and consultations with fetal medicine and midwifery services, and were involved in the development of advance care plans (ACPs). Other services provided to families during pregnancy included memory making, complimentary therapies, and care of siblings. Bereavement support offerings varied depending on the gestation of the child (Table 1).

Termination of pregnancy and hospice care

All hospices responding to the survey accepted perinatal referrals. Such referrals had been received by 90% ($n = 27$) of organizations. Over half of hospices (53%, $n = 16$) suggested families who made an informed decision to terminate their pregnancy following the diagnosis of a life-limiting or life-threatening condition would continue to be offered support by the organization. Most responding hospices who accept antenatal referrals suggested they continue to support

families who are accepted for care and go on to decide to terminate their pregnancy.

> 'we accept referrals for an antenatal diagnosis of life limiting condition and if the family go on to decide to interrupt pregnancy with a termination we would continue to offer full range of support.'
>
> (Hospice 12)

One hospice suggested they offer support during the time of decision making, but when families chose not to continue with their pregnancy, support would no longer be provided.

> 'We may have accepted the referral prior to termination and been part of the discussions with the family regarding their options but would not remain involved if termination was chosen.'
>
> (Hospice 27)

Services offered around the time of birth

Support around the time of birth is not common practice by hospices. Of the hospices that responded, 16.6% ($n = 5$) of the hospices suggested they could attend the birth of babies referred to them if requested by parents, with one hospice offering specific midwifery input. Twenty percent ($n = 6$) of the hospices suggested they offer no services at the time of birth, and a further six hospices provided childcare to siblings, where necessary.

Neonatal care

All hospices who responded to the survey provided hospice-based care for babies following birth. Seventy percent ($n = 21$) of the hospices provided home-based care, and 57% ($n = 17$) provided hospital in-reach, supporting families in postnatal wards and neonatal units.

Hospices discussed working with a range of professionals, implementing ACPs. They described various roles, depending on the content of the ACP, condition of the baby following birth and decisions made by parents:

> '[The specialist nursing team provide] emotional support and guidance during pregnancy but practically become involved after birth to either support memory making, supporting a baby being transferred home or to the hospice to die and they generally lead on compassionate extubation once baby arrives at home/hospice.'
>
> (Hospice 30)

Hospices recognize the need to provide families with opportunities for bonding and attachment, and to be together as a whole family. Organizations highlighted their role in assisting with memory making and allowing families to spend time together. One hospice reported to provide "[opportunities for] memory making, support with anticipatory loss, support for siblings and the extended family" (Hospice 16).

Postnatal care of mothers was indirectly provided by most hospices, through partnership working with local NHS-based midwifery services, which are usually arranged by a community medical practice local to the hospice.

Interprofessional working practices

Hospices reported working with a range of hospital- and community-based professionals and teams, most commonly fetal medicine (70%, $n = 21$) and neonatal services (90%, $n = 27$). Seventy percent ($n = 21$) of those who completed the survey highlighted working with other children's hospices when caring for babies and their families perinatally.

The importance of midwifery input was highlighted by most hospices, with 19 organizations working closely with hospital-based midwifery services, and 17 working with midwives based in the community. Hospices discussed working with neonatal outreach and children's community nursing teams, enabling 24-h access to care and support at home. Half of those replying to the survey ($n = 15$) worked with general practitioners (GPs); this appeared to be in relation to enabling maternal postnatal care and when care was being provided at home.

Advance care planning

All hospice services used ACPs. There was variation in both the role hospice serviced played in developing the plan (Table 2), and the documentation used to report the plan.

There appeared to be some standardization of the forms used to document advance care decisions. In England, the Child and Young Person's Advance Care Plan (CYPACP) was used by most hospice services, although some regional forms were highlighted throughout the country. Some hospices commented on how the CYPACP is not designed for using antenatal care planning, making its use difficult, resulting in local and regional forms. National forms were used

TABLE 2 The role of hospices in developing antenatal advance care plans

Role	Number of hospice services
Coordinate/lead completion of antenatal advance care plans (ACPs)	56% ($n = 17$)
Provide clinical input to ACPs	60% ($n = 18$)
Provide nonclinical input to ACPs	50% ($n = 15$)
Follow, but do not contribute to the content of ACPs	20% ($n = 6$)

in Wales (All Wales Pediatric Advanced Care Plan) and Northern Ireland (Antenatal Palliative Care Pathway).

Some hospices suggested the use of specific forms developed by tertiary centers when accepting referrals of babies who used hospital-based services, which differed between units:

> 'We use CYPACP when working with [one tertiary centre] but when with [another children's hospital] they use their own paperwork to complete an advanced care plan and symptom management plan, which can make things tricky'
>
> (Hospice 23)

DISCUSSION

This study explored the role of UK-based children's hospices in the provision of perinatal palliative care and ACP. Of the 30 hospices that responded to the survey, 90% accepted antenatal referrals, and all accepted neonatal referrals for their care services. Antenatally, care services predominantly focused on the provision of emotional support and ACP. Following the birth of the baby, care focused on meeting the clinical needs of the baby, specifically around symptom management and end of life care. Care offered following the birth of a baby also included care after death, and emotional support and bereavement care to parents and other family members.

All hospices recognized their role in providing emotional support however, approaches taken to meet the emotional and bereavement support needs of parents and other family members varied around the UK. The importance of establishing and maintaining an effective therapeutic relationship between parents and professionals is widely reported in the literature (Branchett & Stretton, 2012; Crawford et al., 2021; Fleming et al., 2016). This is a role that hospices took seriously.

All organizations discussed achieving a balance between meeting the biopsychosocial needs of babies, their parents and family members, from the point of referral, throughout the pregnancy, life and in their bereavement care offer. Advance care plans, in various forms, were commonly used to enable improved quality of life and to relieve suffering, balanced with curative treatment options (Akyempon & Aladangady, 2021) and parallel planning (Sidgwick et al., 2019), in an attempt to identify and achieve value-based goals of parents and other family members (Brunetta et al., 2022; Quinn et al., 2020).

Described as a cornerstone of nursing (Tatterton & Walshe, 2019), family-centered care (FCC) is widely regarded as a fundamental component of neonatal, child, and adolescent health care (Foster & Shields, 2020; Kuo et al., 2012; Shields, 2018; Tatterton et al., 2021). The positive effects of FCC on parents cannot be overstated. Benefits include reduced stress, anxiety, and depression (Ding et al., 2019), improved partnership and decision making, and easier transitions (Vetcho et al., 2020). Vetcho et al. (2020) note that approaches to FCC are commonly only partially realized in the neonatal setting, particularly the therapeutic relationship between parents and professional. Feedback from hospices demonstrated a commitment to FCC at all stages of involvement. From the point of referral, families were supported to make and change decisions, reflecting the complexity and dynamic nature of their situation (Allen, 2014). This support often extends to support families who opt for medical termination of their pregnancy, following which women (Kersting et al., 2007, 2009; Korenromp et al., 2009) and their families can experience long-lasting psychological effects, including posttraumatic stress and intense grief (Hanschmidt et al., 2018). This experience can be further compounded by disenfranchisement, due to social and emotional isolation (Abraham & Hendriks, 2017; Lafarge et al., 2014) and reduced opportunities for support.

In addition to working closely with families, hospices discussed the necessity of working with other teams and services to meet the needs of families throughout the perinatal period. There is clear correlation in the number of families supported by hospices and interagency working. Higher numbers of referrals were reported by hospices that work closely with allied agencies, particularly fetal medicine and neonatal teams, and by those who offered hospice-led services that were delivered in the hospital setting. These relationships were strengthened by regular meetings, joint education, and training and the development of pathways. The value of parallel planning is widely discussed in children's palliative care literature (Bendle & Laddie, 2019; Jack et al., 2018). An interdisciplinary, multiagency approach to care allows this (Price et al., 2019), resulting in a care experience that is dynamic, relevant and based on the uncompromised choice of parents (Mendizabal-Espinosa & Price, 2021).

The combination of a family centered, biopsychosocial approach to care, delivered in a multiagency, interprofessional manner leads to positive experiences for parents (Danguecan et al., 2021), and responsive (Jonas et al., 2020), effective symptom management (Moore, 2018). These factors lead to better bereavement outcomes (Zimmermann et al., 2022), owing to the sense of validity and control perceived by parents (Verberne et al., 2019). ACPs can be useful in strengthening relationships between parents, professionals, and teams, enhancing the interdisciplinary, multiagency approach, and care experience of parents (Orkin et al., 2020), owing to parental confidence in the ability of agencies to meet the needs of their baby (Ananth et al., 2022).

Strengths and limitations

This study is the first to explore the role of UK children's hospices in the planning and provision of perinatal palliative care. The coproduction of this research, with a clinical and academic team of researchers, strengthened the discussion and reducing subjective bias (Galdas, 2017). The findings are internationally relevant to those involved in perinatal, fetal, and maternal care, adding to the literature on FCC, palliative care, and interprofessional working. Nonetheless, this paper should be considered within the context of limitations. Although 54% of hospices responded to the study, the variation of geographies and populations served by individual organizations may

mean that the findings are not representative of all hospices. Finally, the use of a survey to collect qualitative data may have impacted on the disclosure of participants by limiting their responses, or the research team misinterpreting those responses provided (Evans & Mathur, 2018), however, the approach can be useful to map consensus (Norman & Sjetne, 2017).

CONCLUSIONS AND RECOMMENDATIONS

This study shows that children's hospice services play an important and growing role in the perinatal care of babies and families following the diagnosis or recognition of a LLLTC. The family-centered approach to care, from a broad, biopsychosocial perspective means that hospices make a unique and meaningful contribution to both the clinical and psychological needs of families of babies, antenatally, in the neonatal period and after death. Hospices recognized the importance of establishing effective therapeutic relationships with families and of providing emotional support to parents throughout their journey, including when families opt to terminate their pregnancy.

Advance care plans were used by services to enhance and support interprofessional working, while keeping parents and their babies in the center of the planning and delivery of services. The utilization of care pathways strengthen and consolidate multiagency working and improve parallel planning. Family experience is enhanced when an interdisciplinary, multiagency approach to care is taken. This enables the delivery of care that is responsive and dynamic, offering flexibility to families at all stages of their perinatal journey.

CLINICAL RESOURCES

International Children's Palliative Care Network: https://www.icpcn.org/. Together for Short Lives. Perinatal Pathway for Babies with Palliative Care Needs: https://www.togetherforshortlives.org.uk/resource/perinatal-pathway-babies-palliative-care-needs/.

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CONFLICT OF INTEREST

The authors declared no potential conflict of interest with respect to the research, authorship, or publication of this article.

SIGMA THETA TAU INTERNATIONAL CHAPTER

Phi Mu (MT is a Sigma member).

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