

**Title:**

Family centred neonatal palliative care in children's hospices: a qualitative study of parents' experiences.

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## **Abstract**

Since 1982, children's hospices in the UK have provided services where families can care for their children at the end of life (EOL) in a less medicalised environment. More recently, the services of many children's hospices have extended to newborn babies and their families. This paper explores the experiences of three families (five parents) who availed of children's hospices services when their babies required a palliative approach to care. Early diagnosis of a life-limiting condition in pregnancy allowed advanced care planning and enabled parental participation in decision-making before birth. A homely environment, as well as constant support and a sensitive approach from expert staff encouraged parental involvement in all aspects of their baby's care whilst in hospice. Extended time with their baby after death enabled parents to feel connected with their infant. The holistic and family-centred approach to care from children's hospices is highly valued by parents of newborn babies.

## **Keywords**

Neonatal, palliative care, children's hospice, family-centred care, referral.

## **1. Introduction**

Technological advances such as enhanced antenatal screening have resulted in an increased number of babies being diagnosed with a life-limiting condition whilst in utero; providing an opportunity to develop an advanced palliative care plan even before birth (Jackson and Vasudevan, 2020). Whilst termination of pregnancy may be the option for some families, others may choose to continue with the pregnancy for a variety of reasons. In some other cases, babies might be diagnosed with a life-limiting condition at or after birth but despite medical intervention, will still die within hours or days. In either case, these babies and their families require a palliative approach to care (Peacock et al., 2015). Around 2,000 neonatal deaths occur each year from causes likely to require palliative care (Bliss and Together for Short Lives, 2012) with 98% of these deaths happening within the hospital setting (ACT, 2009).

A 'Neonatal Pathway for Babies with Palliative Care Needs' (ACT 2009) was developed in response to an increased awareness of the very specific needs of infants with palliative care needs and their families (Mancini 2011). Despite choice of location of death being central to the pathway, Soni and colleagues (2012) highlighted that parents were seldom given choices about the location of their babies' end of life care (EOLC). The subsequent NICE guideline (2016) for EOLC for children (including babies) and the updated ACT pathway (TfSL, 2017) continue to reinforce the centrality of ensuring 'choice' for families about care and location of care.

Since 1982, children's hospices have been integral to the children's palliative care model in the UK. It has been strongly suggested over the years that newborn babies and their families would also benefit from end of life (EOL) services (Williamson et al., 2009, Soni et al., 2012, De Rooy et al., 2012; Jackson and Vasudevan, 2020). Such possibilities have been described by Wilkinson (2013) as the final frontier in the development of palliative care.

A recent paper describes the efforts of staff in three children's hospices to respond to the infants' and families' specific needs, ensuring individualised care; it also identifies the barriers they experience in reaching out to neonatal units to promote their work (Price and Mendizabal, 2019).

Little is known however about parental choice and decision making with regards to including hospice care for their baby with a life limiting illness. Thus, this paper looks at the experiences of parents who availed of children's hospices services when their babies required a palliative approach to care.

## 2. Methods

This paper emerges from a larger qualitative study that examined the perspective of hospice staff, junior neonatal nurses working in hospital and parents, regarding their experiences of referral and care of newborn infants in children's hospices.

Findings from the thematic analysis (Braun and Clarke, 2006) of parents' stories, help us better understand parents' experiences of living through the birth and death of a baby, as well as the role that hospice played in such experiences. Parents from three hospices in the south of England were invited to take part. Eligibility criteria included having accessed EOLC of their newborn baby or care of the child and family after death within the last 24 months. Three families (two fathers and three mothers, n=5) participated in a face-to-face, in-depth interview by the same experienced researcher (removed for peer review) who used a topic guide to ensure the study aims were included. To ensure rigour the data set were checked by both researchers (removed for peer review) and future analytical direction discussed.

Ethics approval was given (16/EC08/0042) and a support strategy was in place for both participants and the researcher given the emotive content of the subject under investigation.

### 2.1 Setting the context

Children's hospices provide a range of services for babies, children and young people focusing on holistic care for the child and whole family. Children's hospice services can provide such care in a child and family-friendly building and/or in the family's own home, referred to as 'hospice at home' (Price and Mendizabal-Espinosa, 2020). Whilst the specific services may vary slightly across hospices, the main care/services provided are indicated in Figure 1.

Figure 1: Services provided by Children's Hospices (adapted from Price and Mendizabal-Espinosa, 2020)

- Specialist short breaks
- Telephone advice/support
- Specialist therapies, including physiotherapy, play and music therapy
- Access to emergency care
- End of life care (EOLC)
- Care of the child and family after death
- Bereavement care and support for the family
- Information, support and training for parent/carers
- Care for the wider family including siblings and grandparents

Families with a baby with a life-limiting condition may access different services at different stages of the baby's life/illness trajectory. The stories told by parents about their children in this study indicate the variety of services used by families who were availing of palliative care for their baby from a children's hospice. Figure 2 provides a summary of the baby stories that were included in this study.

Figure 2: Summary of baby stories included in the study

- *Baby Alex*

Baby Alex was diagnosed with a life-limiting illness early in pregnancy. Her parents learned about EOL in children's hospices through a midwife during a pre-natal appointment. Both parents felt very strongly about continuing with the pregnancy, in spite of repeated offers by healthcare staff of a termination. Alongside the midwife and hospice staff, they developed a parallel palliative care plan, considering different possible scenarios. A couple of days after birth, she was transferred to hospice. With her siblings, they were able to spend time as a family and helped to create memories until she passed away in her mother's arms. To date, the family enjoy going back to the hospice and spend time in the gardens and play areas.

Hospice Services accessed – *Information and support before birth, EOLC in children's hospice, Care of the child and family after death, Bereavement care.*

- *Baby Aaron*

Baby Aaron was found to have a life-limiting condition at the end of his mum's pregnancy. His parents learned about the children's hospice through a liaison practitioner soon after birth. They transferred to hospice for EOLC as soon as the doctors decided they could not offer medical treatment. Family members came to meet Aaron whilst in hospice. He passed away in his parents' arms having survived longer than expected.

Hospice Services accessed – *EOLC in children's hospice, Care of the child and family after death, Bereavement care*

- *Baby Sam*

Baby Sam was born at term and taken to the neonatal intensive care unit as an emergency because of problems with her breathing. After several tests, she was diagnosed with a life-limiting condition. Soon after, the palliative care team from hospice became involved, helping Sam's parents and hospital staff with different aspects of comfort care; she passed away in hospital. Having never held Sam, her parents chose to transfer to hospice where they were able to care for her body in the cold bedroom, until they felt ready to proceed with funeral.

Hospice Services accessed – *Pre bereavement care and support, Post death care in cold bedroom, post death bereavement care*

### 3. Results

Four main themes and 12 subthemes arose from the data analysis and gave us insight into parents' intense experiences and the role of children's hospice within their narrative/experience (See Figure 3).

Figure 3: Themes and Subthemes



### 3.1 Life changing News

The first theme signifies the shifting emotions from happiness/excitement experienced when parents learnt they were expecting a baby to sheer despair, instigated by the ‘life changing news’. The **hopes and dreams** that commenced with confirmation of pregnancy were obliterated when there was an indication that their baby may not survive birth or may die early on in life.

Inherent to preparations prompted by the **life changing news** were a number of **challenging choices**. Despite the chaos caused by learning of their babies identified complex health problems, a strong desire of **as long as we have a baby** seemed to permeate through the resultant devastation.

What was constant in this theme was the uncertainty but sustained hope on the part of parents. Aaron’s dad said:

*“...so we thought OK the baby could be disabled or with special needs, we could live with that as long as we have our baby that’s all that matters”*

For Sam’s parents, **life changing news** were broken after birth, three weeks into their journey in hospital. Sam’s mum recalled thinking:

*“...you just cling onto every kind of hope you know even though it’s all looking bad we thought maybe, maybe ... she’s not dying ... and we’ll just have a very disabled child but we’ll live with that, that is fine everything is better than death”*

As time went on, the reality made parents consider many different scenarios.

### 3.2 What if?

This analytically defined theme indicates the sustained uncertainty, which was indeed the backdrop of their stories. Planning, an element common in pregnancies, seemed to give parents some control in a situation which was completely unexpected and seemed aberrant. What was discernible in these stories was the quite unnatural combined planning for life and death simultaneously. **What if?** Was a constant question for parents and a number of different possibilities were played out within the **planning and preparing**.

Alex's mother said:

*"we got more, the more we'd ever hope for, cause we'd hoped for an hour maybe two was the most we would ever allowed ourselves to think we would get with her, and we got three, three and a half days..."*

Having had a diagnosis early in pregnancy facilitated the planning and preparing:

*"...cause we'd had all the team involved from during pregnancy that's the main thing that helped things go so smoothly as they could when she was born cause then there wasn't a rush so when she started showing any sign of distress they didn't have to go and get a doctor to write things up cause it was already all done"*

Alex's mum

Hope seemed to be fundamental to allow for plans and preparations. Aaron's parents **hoped for the best** as they transferred:

*"...even then [on our way to hospice] there was still a glimmer of hope that if he would breathe on his own and he got through a couple of months he may be able to come back in [to hospital] for something more ..."*

Aaron's dad

Support from expert professionals was crucial, as was awareness of options; **hospice champions** played a key role in ensuring families received information and constant support when having to make difficult decisions and being confronted with confusing choices.

### **3.3 Hello and Goodbye**

This theme contained a plethora of mixed emotions at the time of '**meeting our baby**', which was the beginning of their new relationship. Hearing their baby cry signified life, seeing the baby was a relief and appeared to enable parents to **hold on to hope**. However, any excitement and hope were understandably tinged with sadness, anxiety and continued uncertainty. Amidst all the emotion was a sense of urgency, a race against time to create memories, to develop the relationship and for the baby to be introduced to the family.

*"...the best thing was the fact that we gave [her siblings] some happy memories of this time"*

Alex's dad

The baby's passing signified the **goodbye to dreams**. Regardless where death took place, moving to the hospice facility gave families a much more homely environment and enabled them to spend time together with that time and space being crucial.

*"it's one thing when your child dies but it is another thing to give up the body so soon... I just couldn't let her go and for someone to tell us that we could have more time with her even though she had died it was such a gift so they said that we could take her to the hospice and that they had a cold cot for her there and that just felt immediately right for us"*

Sam's mum

The need to be with their baby after death and as a family permeated the accounts of parents. The cold bedroom in the hospice allowed precious time together and enabled a gradual separation. The professional expertise and environment were crucial to this theme. Help with planning for the funeral was also valued.

### **3.4 Being together and being supported**

All three families spent time at the children's hospice at and or after death and for bereavement care. This theme captured that sense of togetherness within the supportive hospice environment which included siblings and extended family, something not possible in the hospital. The expert professionals at hospice were credited with enabling the promotion of family unity and spend precious time as a family. Further, the hospice team guided parents to make memories and collect mementos, things they said they would never have thought of themselves amidst their immediate feelings of grief and loss.

*"I feel in the devastation was such a blessing and when we arrived they did things that now we so appreciate but you wouldn't- you can't think straight like taking photos in the garden it's the only photos that we have of sort of no hospital tubes and even though she was dead she looked like a sleeping baby you know so and they did like hand moulds..."*

Sam's mum

Whilst the death of their infant was life altering, the sense was that the hospice provided an expert space in such a difficult situation. The flexible approach to care in hospice and unachievable, as parents saw, in hospital enabled the making of precious and important memories.

*"I think they really got the balance right between letting us do our thing but then being there if we needed extra support I think that was really amazing"*

Aaron's mum

The strong foundation of support offered by the hospice immediately after the baby had died was also seen as important to the ongoing bereavement care provided enabling families to create **a new normality**. This recognised that the birth and death had changed family dynamic forever.

The hospice held a **special connection** for all the parents within their narratives and families continued a relationship with hospice (through for example the memorial service and coming back to visit). In so doing, parents maintained a bond with their baby as signified by the child's birth date and death date recorded on a stone in the hospice pond, or the strong relationship with the staff who had guided them so expertly through their painful journey.

*"So I went there [to the hospice] actually last weekend just for [Alex's siblings]... we were there for the morning and stayed there for four five hours..."*

Alex's dad

The special connection with hospice was not solely experienced by parents but also grandparents, siblings given the family centred approach to care. A feeling of being **forever grateful** given the holistic and family-centred approach to care transpired in parents' accounts and was evident in activities such as fund raising and volunteering.

## **4. Discussion**

Regardless of the uniqueness of the accounts, all charted a painful and emotional journey, which centred unequivocally round their unique situation and timing of their baby's birth and death. All the stories were punctuated with emotional and practical chaos as the excitement of a pregnancy switched to a period of uncertainty as the parents navigated uncharted territory (Price et al.2011).

The homely environment, constant support and sensitive approach from staff as well as the opportunity to care for the baby as a family in a private space were common features that families valued from hospice care. This family-centred care (FCC) approach allows parents to 'feel like parents' (Branchett and Stretton, 2012, Cleveland 2008). It is likely that the active participation in care and in the decision-making process gave parents a much needed sense of control and the opportunity to create long-lasting memories.

The experience of Alex's family highlights the relevance of integrating palliative care into pregnancy, timely referrals to neonatal palliative care services give parents the opportunity to be informed, prepare and make decisions. The role of midwives in supporting families and liaising with professionals needs to be enhanced (Price et al, 2019).

Transferring to hospice indicated the beginning of "goodbye" yet, being in hospice allowed for time and space to become a family, to introduce baby to other family members and friends or to take a stroll in the garden, all of which provided a sense of normality within such an alien experience. This seemed to allow hope to move gradually from hope for a miracle (expectational) to hope for a peaceful and pain free death (Keene-Reder and Serwint, 2009).

Trusting relationships became vital when navigating "what ifs", parents were painfully aware of their baby's terminal condition and impending death, while at the same time they held on to hope. Hope seemed to be the drive through such a traumatic experience and the sensitive, empathic and supportive attitude from hospice staff an enabler in the transitioning. The effects of staff's attitudes on parents' experiences might not only be immediate but long lasting (Rini and Loriz, 2007). Parental bereavement following the death of an infant is unique in that parents have less time to spend with their baby and to create memories that will help them maintain a connection with their child after death (Currie et. Al., 2019). The experiences of parents in this study suggest that children's hospices allow for that connection to be maintained over time through extensive memory making, establishing meaningful relations with staff and dedicated memorial events.

#### **4.1 Strengths and Limitations**

The number of participants in this study was small; however, in-depth interviews with parents generated rich data and allowed an insight into their experiences. Limited funding prevented non-English speaking families from participating; in addition to this, the very limited number of potential participants resulted in lack of diversity in the parent sample.

#### **Conclusion**

This study adds to the understanding of the role that children's hospices play in supporting families through EOLC of their newborn and through bereavement. It also highlights the importance of perinatal palliative care in offering families information and opportunities to plan and prepare, so that they have a real choice of EOL place of care and death for their baby. Parents alluded to the significance of hospice offering the time and space that allowed the family to be together, to get to know their baby, make family memories and, sadly, to say goodbye. FCC is at the core of healthcare provision in the UK, but despite the importance of this approach being widely accepted, it has been purported that many pay lip service to the concept within child health care (Shields, 2016). Whilst the hospital environment can be seen as a barrier to FCC (Lloyd et al., 2018) our findings suggest that the hospice environment and the expert staff are enablers to a much more pure approach to FCC. Further research is needed to identify opportunities and barriers to timely referrals of newborn



babies, and to understand more about the needs of parents who chose to access hospice as the place where a FCC approach is adopted when caring for a baby with a life-limiting condition before, during and after death.

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