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## **Ending before it truly begins – the continuing relationship between bereaved parents and their baby as facilitated by a children’s hospice.**

### **Background**

Technological advances such as enhanced antenatal screening have led to increased numbers of babies being diagnosed with a life-limiting condition whilst in the womb; hence, there is an opportunity to develop an advanced palliative care plan even before birth. Such possibilities have been described by Wilkinson (2013) as the final frontier in the development of palliative care. 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 soon 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).

A report from the Department of Health UK (Healthcare and Partnership Analysis, 2007) showed that between 2001 and 2005 there were over 2,000 neonatal deaths per year from causes likely to require palliative care; almost all of these deaths (98%) took place in hospital. In response to the very specific palliative care needs of newborn babies and their families, the Association for Children's Palliative Care (ACT 2009; 2018), now called Together for Short Lives (TfSL), created the 'Neonatal Pathway for Babies with Palliative Care Needs'. An important part of this initiative is to provide families with a 'real choice' of the best place for their baby to be cared for and/or the best place for their baby to die. A year later, the British Association of Perinatal Medicine released guidance on palliative care (BAPM, 2010), which supports healthcare professionals in establishing eligibility of fetus or baby for palliative care. More recent efforts to support babies at the end of life (EoL) and their families include the appointment of the UK's first regional Lead Nurse in Neonatal Palliative Care in 2015. This post is part of a 5-year project will to facilitate expert and autonomous nursing care and the provision of support to neonates, families and unborn babies who require palliative and EoL care. Involving training across London the project's ultimate aim is to support early identification of eligible babies, whilst ensuring that the babies and their families are cared for in the most appropriate environment.

Since 1982, children’s hospices have been integral to the children’s palliative care model in the UK. It has been suggested that newborn babies and their families would also benefit from these services at the EoL (De Rooy et al., 2012; Price et al., 2011). A recent study describes the experiences of children’s hospice’s staff when caring for infants and supporting families throughout this difficult time; it also describes the barriers they experience in reaching out to neonatal units to promote their work (Price and Mendizabal, 2019).

This paper looks at the experiences of parents who availed from children’s hospices services for EoL care of their newborn babies. We argue, that children’s hospices provide a space that allows families to be together and initiate a relationship with the baby even though that baby’s life has ended before it has truly begun.

### **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 infants in children’s hospices. We present findings from the thematic analysis of parents’ stories (n=5) and helps us better understand parent experiences of living through the birth and death of a baby and also the role that hospice played in such experiences. Data were collected

through a one to one face to face interview with a parent by the same experienced researcher who used a topic guide to ensure the study aims were included. Ethics approval was given and a support strategy was in place for both participants and the researcher given the emotive content of the subject under investigation. To ensure rigour the data set were checked with both researchers and future analytical direction discussed.

Data analysis give rise to 4 themes and 11 subthemes that gave insight to their painful stories.

## Results

### ***Life changing News? - uncertainty but sustained hope.***

The first theme signified the shifting emotions from happiness/excitement that they were expecting a baby to despair that was instigated by the 'life changing news'. The excitement was overshadowed when there was an indication that their baby may not survive birth or may die early on in life. What was constant in this theme was the uncertainty but sustained hope on the part of parents as demonstrated by the story told by Ella's parents.

Baby Ella was diagnosed with an incompatible with life illness when her mother was 16 weeks pregnant. Her parents were aware there were great chances of Ella having a genetic condition because they had experienced it with their first pregnancy, which ended in a termination of pregnancy. This was their 3<sup>rd</sup> pregnancy. In one of their pre-natal appointments a midwife told them about the possibility of being transferred to a children's hospice for end-of-life care in the remote case that Ella survived. They both felt very strongly about that option and began to plan for this possibility alongside hospice staff. Doctors felt less comfortable with this decision and continued to offer termination of pregnancy, which Ella's mother found very difficult.

The first theme ***Life changing News?*** Refers to the beginning of the relationship with baby, and the preparations that take place:

- *Hopes and dreams* – Initial excitement shattered by fatal diagnosis.
- *Challenging choices* - For one family a fight against ante-natal diagnosis (refusal of termination of pregnancy) but a possibility to plan ahead (vital time to visit hospice, meet staff, prepare care plan).
- *As long as we have a baby* – Devastating news quickly turn into hope.

*"He'd hoped [Ella's dad]... or his main aim was that she would breathe once she was born so we would have a little bit of time even if it was just an hour... so our hope at the end, once we had the MRI and there was no hope, that she was gonna survive and continue and we fully decided that palliative care was the most appropriate route for her"*

Ella's mum

***What if? – hope for the best.***

Aaron was found to have a life-limiting condition at the end of his mum's pregnancy. Soon after birth, his parents learned about the children's hospice and, as soon as the doctors decided there was nothing to be done, they were transferred for end-of-life care. He survived for longer than expected, to the point where their parents started to hope that maybe he could beat the odds.

- *Planning and preparing* - quite unnatural combined planning that being for life and death at the same time.
- *Difficult decisions and confusing choices* - a number of different possibilities were played out within the planning.
- *Hope for the best* - Desirability hope – hope for time together, hope for quality life, hope for baby comfort

*"...even then there was still a glimmer of hope that if he would breath on his own and he got through a couple of months he may be able to come back in for something more and he was doing great, or at the time we thought he was doing great. Looking back and looking at the photographs you can see his deterioration over time but we didn't quite see that..."*

Aaron's dad

***Hello and Goodbye – hope for a bit more time.***

Baby Sam was born at term and taken to the NICU as an emergency because of her not breathing. She was finally diagnosed with a severe neurological condition after 3 weeks in hospital; at which point the palliative care team from hospice became involved. She died in hospital

- *Meeting our baby* – the beginning of the relationship, hearing baby cry, excitement was tinged with sadness and uncertainty about what was going to happen.
- *There is still hope* - a race against time to create memories, to develop the relationship, for baby to be introduced to the family.
- *Goodbye to dreams* - moving on to hospice was to a much more homely environment, the being able to spend time together and to become a family but marks the beginning of the end – time and space crucial. The need to be with their baby after death and as a family permeated parent accounts. The cold bedroom allowed precious time together and enabled a staged separation. The professional expertise and environment was crucial to this theme. Help with planning for the funeral was also valued. Time running out.

***Being together and being supported –***

- *Enabling a new normality* – enables to be parent, enables family unity, focus on baby, other things taken care of.

*"...a couple of days after [arriving to hospice] that we took him out of the hospice and we went to a cafe nearby and you know it really it's so hard to explain how special it was but how much that made just made everything feel so much better and so much more normal and yeah literally it was just walking down the road having a coffee and walking back but it's the sort of thing we dreamed about doing with the baby and the hospice just made that happen"*

Aaron's mum

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

*"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 and ....so we were able to stay there for a week actually cause they can only keep the body for a week..."*

Sam's mum

- *Special Connection* – baby as a person, as a member of a family, as a sibling, parents as parents. But also, parents continue a relationship with hospice (memorial service, fund raising, volunteering, coming back to visit) and, in so doing, a relationship with baby.

*"So I went there [to the hospice] actually last weekend just for [Ella's brother] cause he loves- he'd go there every day if he could so we went there at the weekend... we were there for the morning and stayed there for four five hours so he got to say hello to all the people he knew and stayed for lunch there and made some mother's day cards and bits and pieces and there and then we came back home"*

Ella's dad

Discussion:

### **Sequestration of death**

Giddens (1991) proposes that with the advent of the modern era death has been hidden from the public sphere, portrayed as negative and dealt with by professionals (hospitals, doctors, undertakers, etc). Characteristics of the modern period are secularisation (death used to be a very public event due to religious ceremonies), professionalization and medicalisation (death as pathological, dealt with in private spaces such as hospitals, guided by medical expertise and power, relatives have little control over what happens at and after the moment of death). Mellor and Shilling (1993) extend the argument by proposing, in a very rational modern time, a way of coping with death is by hiding it in designated places. Scientific discourses and the diminished role of the sacred in religious practices have contributed to the privatisation and individualisation of people's experiences with death and grief. Furthermore, these privatisation and individualisation leave people feeling unease, uncomfortable and vulnerable when dealing with death. Elias (1985) proposes there is now a lack of clarity about what to do and what to say in rituals of mourning that leave people feeling uncomfortable when confronted with these situations.

Until very recently, miscarriages and stillbirths were not talked about. Lovel (1997) argues that death at the beginning of life (either by late miscarriage, stillbirth or neonatal death) has been largely neglected and therefore grief is unacknowledged.

We wonder if this could partially explain why it is so difficult for clinicians to have timely discussions with parents about imminent palliative pathways. Midson and Carter (2010) interviewed parents as part of their implementation project of palliative care in a care hospital. They found that, even though the care pathway was fully advertised and staff had training and support, they were still reluctant to discuss the possibility of death with parents until the very end. Equally, in their retrospective case note review within two NHS Trusts, Heckford and Beringer found that palliative care was discussed later.

Moral order Mary Douglas, babies should not die. As soon as the diagnosis comes – suffering?

Philosophies of care – nursing (quality of care) versus medical (curing/intervention) - denial of death as a legitimate outcome

Family centred care – parenting: hearing the baby cry, holding, introducing to the family and in special to siblings – but family centred care about living or curing?

Parents not wanting to forget, fear to forget

Engaging with families, they want to talk

Time and space

- Personalised care and taking the time to do the 'ordinary' seemingly unimportant thing
- Making places as "good" places for dying
- Convenient timing – good death
- How to identify the time when death is imminent?

Hope

Conclusions:

- Children's hospices enable family centred care at the end of life
- Better understanding of the role of children's hospices in neonatal palliative care
- We need more evidence of what works