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*'Juggling amidst complexity'* – hospice staff's experience of providing palliative care for infants referred from a neonatal unit.

## INTRODUCTION

Since the world's first children's hospice opened in 1982, children's hospices have been integral to palliative care provision within the UK (Lenton et al, 2004), and have been recognised as a model for future development in Europe and globally (Dangel, 2002). Neonatal palliative care is an emerging field within children's healthcare and neonatal care; medical and technological advances have led to increasing numbers of babies diagnosed with life limiting conditions, even before birth.

Developments include the perinatal palliative care pathway which states parents should have choice regarding location of their baby's care (ACT, 2009; TfSL, 2017). Efforts to improve care and professional support based on the needs of babies and families in the UK include the development of a neonatal palliative care education programme in London (Mancini, 2010) and ~~some~~ collaborative work between hospital and a number of local children's hospices (Williamson, Devereux and Shirliffe, 2009).

Further, it has been proposed that newborn infants and families could benefit from the experience available in children's hospices (de Rooy et al, 2012). Despite resources and availability of children's hospices, families are not consistently being offered such an alternative in the UK (Craig and Mancini, 2013). A national survey with 29 tertiary neonatal units highlighted that, whilst local hospices were available to 93% of units participating; only 63% referred babies (Soni et al, 2011).

Brosig (2007) examined parents needs during their infants' end-of-life care identifying that honesty, empowered decision making, parental care, environment and faith/trust in nursing care were important to parents. A study examining parents' experiences living through the death of a child provided an early indication of potential value for infants transferred from neonatal units to hospice (Price et al., 2011). Substantive research remains limited. Therefore, this paper aims to explore hospice professionals' perspectives regarding the provision of neonatal palliative care including the challenges and opportunities experienced.

## METHODS

Qualitative methodology addressed staff experiences (Silverman 2000). Data collection involved focus groups with hospice staff in three South of England children's hospices. Seventeen people (from care teams made up of nurses, specialist nurses and support workers) participated in three focus groups. Two groups took place outside hospice whilst the other took place within hospice. Groups were digitally recorded and transcribed by one author (RM) who facilitated the groups. Ethical permission was granted (16-IEC08-0042).

Participants received written study information, had the opportunity to ask questions before signing a consent prior to participation Data was stored per University guideline. All names were changed to maintain confidentiality. A follow up support strategy was in place for participants if needed.

Data analysis involved both researchers (JP/RM) who independently analysed each data set. A thematic analysis was adopted keeping research questions in mind alongside searching for patterns to form themes and sub-themes (Braun and Clarke, 2006). Such an approach ensured rigour and ensuing discussion guided future analytical direction.

## FINDINGS

One overarching analytically derived theme, four main themes and 12 subthemes arose from the data enabling further understanding of hospice staffs' experiences caring for infants and families (Figure 1).

'Juggling amidst complexity' is the over-arching theme integral to all professionals' stories of caring for neonates in hospice. It highlights powerfully the complex and unpredictable nature of the infant's life trajectory. Juggling involved a lot of doing for staff and happened against a backdrop of the clock ticking. The juggle captures the sense of navigating different challenges and opportunities

whilst striving to push the boundaries in providing best care and is seen in four distinct yet inter-related themes.

### 'Bringing the sides together'

One of the complex challenges identified was the notion of 'Bringing the sides together'; which involves a 'them and us' type scenario in the provision of care for infants at the end-of-life. The notion of the baby and family being betwixt and between hospital and hospice permeated the data -

*'I only came into hospice care at the beginning of last year so my experience is mainly based on em...palliative and end-of-life care with- in a hospital so it's been really interesting for me to see the other side within hospice'*

Hospice staff had pride in what they could offer whilst at the same time recognised the expertise within neonatal units in providing care. Yet, they expressed a sense of frustration that they could not always reach families that could potentially benefit from hospice care when cure was no longer possible. Whilst an increased number of referrals was discussed by hospice staff participants (including antenatal) the sense was that there was still progress to be made in bringing different sides together more successfully and consistently -

*'We are working as separate entities, and there's bits of us that are working together but it's not the whole thing'*

'Bringing the sides together' thus was about the desire and determination voiced regarding the wider strategic picture of hospices and hospitals working together. Such a division in terms of sides required juggling and was frustrating for professionals. A number of ideas about 'Bringing the sides together' were offered including imparting information about hospices' services and continuing education around palliative care. Participants felt that recent education efforts in their area helped hospital staff gain insight regarding what children's hospices can offer. Such education needed to be ongoing given the transient nature of staff in neonatal units -

*'You know that model (education across the city) has worked and it's- but the trouble is, because of staff turnover anyway whether it's hospice or hospital you have to keep revisiting'*

Sending staff from hospice into neonatal units, to ensure more cohesive 'team-working' with hospital staff was viewed as another way of ensuring partnership working (such as the role of specialist palliative care nurses in some hospices) -

*'We kind of need to raise awareness in the NNUs about the offer of palliative care and the offer of children's hospices and we almost need to market ourselves in the NNUs...'*

Building relationships and confidence in hospice service was part of branching out -

*'We are starting to build sort of relationships with certain hospitals but... there are certain hospitals, you do one and one case goes well and then you start getting other referrals but there are other places where we haven't ...I think there are probably pockets that in certain hospitals they don't realise what there is for these families still'*

Ensuring consistency was identified as a challenge bringing the sides together due to multiple children's hospices in the area. The fact that a unit may be dealing with two or three children hospices meant that referral criteria, policies and services were often different -

*'And because hospices are independent organisations there's no, there's no, consistency in how they work'*

Such differences created problems for staff in terms of communication with families, which in turn could negatively impact the therapeutic relationship.

#### Holding on and letting go

Another challenge to juggle was the complexity identified around what hospice staff saw as 'Holding on and letting go' and was highlighted by an apparent struggle during the process of referring to other services. Arising from what participants saw as professionals *being possessive* holding on to the babies and families appeared two-fold, borne from lack of knowledge and trust about what children's hospices can offer but also about the possible assumption that 'they' (hospital staff) knew what parents want. It was also recognised that parents may feel safe in the high technological

environment of the NNU and felt reluctant to leave. The juggle was compounded given the uncertain nature of the infant's condition.

Past good experiences with previous babies at hospice seemed to propel the decision to commence referral to hospice. However, the referral process was not always planned in advance, leading to multiple problems for hospice.

A natural flow of timely, thought out referrals helped in achieving an equilibrium; this included family choices from an early stage. Thus, timely referral was seen as key to decision-making. There was also the recognition that such equilibrium was not always achievable given the complexities of some babies' care. The sought after balance was viewed as crucially involving forward planning so that if the baby went to hospice and survived there was a 'fall back plan' with the hospital (the children's ward rather than the neonatal unit), but this at times did not happen as hospitals had gone through the process of letting go and moving on.

### Shifting Focus

'Shifting focus' was the third complex area identified by hospice staff emerging from the interplay between uncertainty and expectations. Discussions revealed the uniqueness of each infant's healthcare journey. Thus, in providing best care, staff were required to be responsive, shifting focus accordingly, keeping an 'open mind' whilst working in partnership with parents and hospital staff.

Hospice staff considered that, in the current atmosphere of constant scientific evolution, the outcome of a life-threatening condition might only be temporal; therefore, they needed to be open to changing expectations. Furthermore, they needed to keep in mind the individual and very particular health trajectory of each baby and the fact that, in some cases, expectations around life and death might change 'unexpectedly'.

Hospice staff thought that a layer of complexity was added when parents' expectations were impacted by technological and medical advances, with social media playing an important role in shaping expectations -

*'...with social media parents' expectations...they hear that one child had surgery in America, they want that you know, the nucleoside treatment for the metabolic conditions...you know we are seeing the effect that has in other families'*

There was a strong view that, whenever possible, ante-natal referrals were most appropriate and gave professionals a chance to begin to work with a family and plan. However, it was argued that hospital healthcare professionals sometimes imposed their own expectations and held ante-natal referrals back -

*' To see if the baby would survive post-birth and then they ring us when it [sic] has survived whereas actually we could do a lot even if that baby doesn't survive ...'*

Uncertainty seemed to permeate every aspect of perinatal and neonatal palliative care, giving rise to a sense of urgency as indicated by participants in preparing themselves, other professionals and parents to expect different possibilities and shift focus accordingly. Participants felt families needed to be prepared to expect the unexpected within their baby's life trajectory, and this included being given different 'scenarios' and being aware that it is difficult to predict a time-frame for dying. Nonetheless there was a view that families were sometimes given a very final end-of-life scenario in hospital, which reinforced expectations that were difficult to change. Thus, hospice staff expressed a deep sense of frustration when families of new born babies were referred to hospice for their babies' end-of-life care, without having been given a parallel scenario -

*'There are so many families who have been told your baby has got a condition that is incompatible with life and it's just very final and very- and then long behold actually they don't die...'*

Open mindedness seemed a key element in dealing with the uncertainty of each baby's life trajectory. However, hospice staff made it clear that, for them, open mindedness was not only about expecting the unexpected in the baby's healthcare path, but equally important was openness about parents' needs, wishes and expectations.

Amidst the uncertain environment that prevailed, hospice staff felt they needed to be prepared to change direction by responding to the baby's evolving needs, whilst working in partnership with the family. In participants' view, preparation for expecting the unexpected facilitated a change in direction if needed. A baby surviving longer than expected or a change from end-of-life to continuing care were two common changes in direction discussed-

*'Then our service goes into a completely different mode and what we can offer completely changes because we can offer long-term services and community support and therapeutic- well we can always offer therapeutic services but I think yeah the whole dynamics change where we are going, what we are doing with that family, how we respond to them how we'd care for them and the plan completely changes but yeah sometimes we are not so good at preparing families for that change.'*

Participants' revealed a concern that, once a baby was referred for end-of-life care, hospital staff let go and moved on without considering alternative outcomes, so that if the baby survived then there was no plan. Recent experiences raised awareness for hospice staff that a change of direction was always a possibility. Hospice staff spoke about the need to be open minded and alert to the signals that would warrant a shift in focus.

### Adapting Care

Participants referred to actions required in order to respond to the infants' and families' specific needs, ensuring individualised care. This was captured by the distinct yet interconnected theme 'Adapting care'. Participating hospices appeared well equipped to respond to the specific needs of



each baby and family; one of the main goals being allowing the family to be a family. The less hectic hospice environment was perceived as valuable not only for ensuring 'space' to make memories but for giving families time to process the difficult experience they faced and deal with mixed emotions. Creating some normality included providing an atmosphere where parents could stay with their baby 'comfortably', have visitors and very importantly, welcome siblings.

Greater opportunities for memory making were discussed as a distinctive characteristic of hospice care -

*'I mean certainly the big difference that I've noticed is the opportunity for so much memory-making...somehow in a hospice it seems it's done in a much calmer em...how can I explain it?'*

Responding to the unique needs of infants and their parents could only be accomplished by finding a balance between providing support and education, whilst at the same time knowing when to step back; effectively allowing the family to be a family. Participants' accounts revealed that, even though caring for new born babies might be challenging, as children's nurses they felt prepared and had transferable skills for doing so. The different support needed by mothers and fathers, and the associated challenges were discussed by staff.

Mothers were identified as having 'midwifery needs' and it was suggested that not all hospice staff had the same awareness about these needs -

*'...going back to making sure that we met the midwifery needs of the mother you know what was she gonna do because she had these breasts that were really sore...'*

Participants argued, in being attentive to mothers' needs through the pathway from giving birth through to bereavement, that fathers' emotional needs might be overlooked. Similarly, sometimes the communication was through one parent, commonly the mother. Again, participants felt the father might be excluded. Thus, finding a balance when communicating with parents was viewed as essential.

Further parents' and staff members' expectations also needed balancing in order to reach the desired level of care. On one hand, participants felt the hospice ethos encouraged parents to be parents, while on the other, parents' expectations might be that, as in the hospital, staff undertake their baby's care. Reconciling these expectations was imperative. Discovering parents' wishes, rather than assuming, was viewed as crucial but equally important was helping parents consider options that might not be obvious to them -

*'But it's also if they are being tube-fed if they want to express...it's actually asking them what they want but also getting them to think about what they want because they are probably bamboozled...finding a balance between allowing them to be... but also allowing them to find out what they want.'*

Participants were concerned about parents' possible loss of reassurance upon moving from the highly technological hospital environment to hospice. This needed balancing and for some involved *'showing them gradually and gently a different way'* to facilitate adaptation.

### DISCUSSION

The study made clear that providing neonatal palliative care was complex requiring professionals to work in partnership with parents to juggle a number of issues and choices. One major complexity was an apparent struggle between hospital and hospice staff regarding where the best place and who the best people were to provide palliative care for infants. Expertise of both staff on neonatal units and children's hospice in providing quality care is clear however, this struggle becomes a barrier to timely referral or even any referral to hospice. Whilst participants recognised that hospice was not for all infants and their families, they desired a more consistent consideration of the benefits of hospice care, where hospice was offered as an option to parents and where they were supported to make an informed choice. The negative connotations associated with the word hospice and a lack of understanding of what hospice offered was suggested as a possible reason for hospital staff's reluctance to offer hospice to parents; this is consistent with earlier studies (Kirk and Pritchard, 2011; Price, McCloskey and Brazil, 2016). Part of such reluctance appeared to be a

common continued strive within the neonatal environment to cure and/or aggressively treat often leaving little or no time to present options to families, or on occasions last minute referral. Thus, finding a balance often appears part of a complex juggling act which should helpfully involve working collaboratively around timely referrals (Midson and Carter 2010). Continuing education therefore seems crucial in ensuring hospital staff have an awareness of services that hospices can offer and also have an awareness of how to implement palliative care in hospitals so that babies who cannot transfer to hospice can still avail of skilled palliative or end of life care. ACT (2009) updated by The Together for Short Lives (2017) neonatal pathway is one way of ensuring such an awareness, but this study highlighted the perception that the pathway was not used regularly in neonatal units. Such findings resonate with a previous study by Gallagher et al (2012) which showed that a high number of respondents to their survey felt they had not received enough education in children's palliative care, and few participants were aware of the ACT pathway. Therefore, this study supports the notion that healthcare professionals perceive a general lack of educational preparation for caring for infants and children who need palliative care. Further there is the need for continued relationship building and the developing of connections across teams.

Integral to *adapting care* is the juggling of changing expectations, different scenarios, possible changes of direction in addition to each individual babies' and families' needs. The gap currently still in existence could be bridged as professionals see it both in terms of raising awareness and working together to ensure families have choices. Thus, advanced planning appears crucial if parents are to be supported to consider all potential outcomes. Similarly, an earlier study, highlighted how poor advanced care planning had a detrimental impact when the discussions of end-of-life came in the later stages (Heckford and Beringer, 2014). Bringing the sides together should also involve liaising with midwifery as hospice staff at times felt unsure how to care for mothers' physical needs.

### CONCLUSION

This study highlights that hospice staff believe that hospice provides an environment where skilled practitioners can enhance the quality of palliative and EOL care for babies and families. Professionals have expertise to provide individualised flexible care in a homely and relaxed environment for infants at the end-of-life and their families. However, challenges exist in ensuring families have choice and that referral to hospice is timely. Central to enabling choice for families is education for all health and social care professionals regarding what hospice can offer and the associated referral criteria. Hospices and neonatal units must work together to build relationships and start conversations about the needs of babies and their families. The study indicates TfSL (2017) perinatal pathway can assist professionals in ensuring choices are given to families. Alongside presenting new and important findings regarding the complexities regarding referral and potential value of hospice, clear implications for practice regarding neonatal care about juggling such complexities have been presented. Future studies need to examine perspectives of staff working in neonatal units to gain insight into their practices regarding implementing palliative care for infants and their families and to explore their views on planning and offering families choices.

## References

- Association for Children's Palliative Care (ACT) (2009) 'A Neonatal Pathway for Babies with Palliative Care Needs'. ACT: 2009.
- Braun, V., Clarke, V. (2006) 'Using thematic analysis in psychology, Qualitative Research', *Psychology*, 3:2, 77-101
- Brosig, C.L., Pierucci, R.L., Kupst, M.J. and Leuthner, S.R. (2007) Infant end-of-life care: the parent' perspective. *Journal of Perinatology*, 27, 510-516.
- Craig, F. and Mancini, A., 2013, April. Can we truly offer a choice of place of death in neonatal palliative care?. In *Seminars in Fetal and Neonatal Medicine* (Vol. 18, No. 2, pp. 93-98). WB Saunders.
- Dangel, T. (2002) The status of Pediatric Palliative Care in Europe. *Journal of Pain and Symptom Management*, 24, 2,160-165.
- De Rooy, L., Aladangady, N. and Aidoo, E., 2012. Palliative care for the newborn in the United Kingdom. *Early human development*, 88(2), pp.73-77.
- Gallagher, K., Cass, H., Black, R. and Norridge, M., 2012. A training needs analysis of neonatal and paediatric health-care staff in a tertiary children's hospital. *International journal of palliative nursing*, 18(4), pp.197-201.
- Heckford, E. and Beringer, A.J., 2014. Advance care planning: challenges and approaches for pediatricians. *Journal of palliative medicine*, 17(9), pp.1049-1053.
- Kirk, S., & Pritchard, E. (2012). An exploration of parents' and young people's perspectives of hospice support. *Child: Care, Health and Development*, 38(1), 32-40
- Lenton, S., Franck, L. and Salt, A. (2004) Children with complex health care needs: supporting the child and family in the community. *Child: Care health and development*, 30, 3, 191-192.
- Mancini, A., (2010) Developing a neonatal palliative care education programme within the North West London Perinatal Network. *Journal of Neonatal Nursing*, 17(4), pp.146-149.
- Mancini, A., Uthaya, S., Beardsley, C., Wood, D., & Modi, N. (2014). Practical guidance for the management of palliative care on neonatal units. Royal College of Paediatrics and Children Health. Chelsea and Westminster Hospital. Retrieved August, 27, 2014, from [www.chelwest.nhs.uk/services/childrens-services/neonatalservices/links/Practical-guidance-for-the-management-of-palliative-care-onneonatal-units-Feb-2014.pdf](http://www.chelwest.nhs.uk/services/childrens-services/neonatalservices/links/Practical-guidance-for-the-management-of-palliative-care-onneonatal-units-Feb-2014.pdf)
- Midson, R. and Carter, B., 2010. Addressing end of life care issues in a tertiary treatment centre: lessons learned from surveying parents' experiences. *Journal of Child Health Care*, 14(1), pp.52-66.
- Peacock, V; Price, J and Nurse, S (2015) Pregnancy to Palliative Care *The Practising Midwife*, Volume 18, 10, pp. 18-23(6).
- Price, J., Jordan, J., Prior, L and Parkes, J (2011) Living through the death of a child: A qualitative study of bereaved parents' experiences. *International Journal of Nursing Studies* (2011), doi:10.1016/j.ijnurstu.2011.05.006
- Price, J McCloskey S and Brazil, K (2018) The role of hospice in the transition from hospital to home for technology-dependant children. *Journal of Clinical Nursing*, 27 (1-2), 396-406.

Journal of Neonatal Nursing

2,500-3,500 words, including abstract and in-text references

Silverman, D. (2000) *Doing Qualitative Research. A practical handbook*. London, Sage.

Soni R., Vasudevan C., English S. A national survey of neonatal palliative care in the UK. *Infant* 2011; 7(5): 162-63. 1

Together *for Short Lives* (2017) Perinatal Pathway for Babies with Palliative Care Needs: Available at <https://www.togetherforshortlives.org.uk/resource/perinatal-pathway-babies-palliative-care-needs/>

Wilkinson, D (2013) We need palliative care for babies facing certain death. *The Conversation*, available at: <http://theconversation.com/we-need-palliative-care-for-babies-facing-certain-death-15932>

Williamson, A., Devereux, C. and Shirtliffe, J., 2009. Development of a care pathway for babies being discharged from a level 3 neonatal intensive care unit to a community setting for end-of-life care. *Journal of Neonatal Nursing*, 15(5), pp.164-168.