

**ICPCN Buenos Aires, Argentina, 18 – 21 May, 2016**

**Author:** Dr Kerry JONES

**Affiliation:** University of Exeter Medical School, UK

**Title:** [Support and Critical Communication in the Parental Perinatal Death Experience](#)

**Key words:** Neo natal, end of life, paediatric palliative care.

### **Background**

The death of a child following stillbirth, premature birth or neonatal admission represents for many parents, an unexpected and challenging event. Health professionals in maternity and neonatal services are often involved in with patient's families during such difficult times. I demonstrate, that for many parents, communication and the support that health professionals provide, can mediate parental responses to their infant's death. A vital aspect of this care is the recognition of the significance of the death of their infant. What I argue for is that there is an opportunity to forge a relationship of trust necessary to provide optimal care for patients and their carers and with a real need of a perinatal death care pathway.

Advances in treatment and technology have led to increasing demand for highly technical perinatal and neonatal care services. Despite, such innovations, stillbirth rates have altered little from 1 in every 200 birth stillbirths and despite some improvements for neonatal deaths, in 2007 and in England alone for example 2000 babies died in the neo natal period. Just to set these figures into context in this presentation, stillbirth is referred to as a death in the UK which occurs following 23 weeks and 6 days gestation. Neo natal death is referred to as those deaths which occur in the first four weeks of life (Centre for Maternal and Child Enquiries, 2011).

## **Method**

This is a qualitative study in which 30 parents were recruited from the southwest and north of England.

Parents were recruited through organisations which support parents following the death of their baby in the form of groups run by trained facilitators. Facilitators acted as 'gatekeepers' and distributed information which invited potential participants to the study. Following a screening interview to ensure the inclusion and exclusion criteria were met, formal consent to participate was sought.

As with any research of a highly sensitive nature, parents were reminded that consent was ongoing and that they had the right to withdraw at any time without consequence.

In drawing on these experiences, a voice centred relational method was employed to analyse data from 30 semi structured interviews and six focus group discussions with parents. This particular method as framed by Brown and Gilligan (1993) at Harvard University emphasises the notion of relational ontology as based on the premise that humans are embedded in a web of complex and intimate social relations.

This ontology then, considers the self in relation to others. It further permits a consideration of parent's narratives in light of the relationships to people and to the boarder social, structural and cultural contexts within which they live and how this

impacts on their daily life following loss. Transcripts and recordings from interviews and focus groups were read at least four times, coded and thematically developed to ensure there was no loss to the context of the parent's lived experiences.

In the third particular reading of parents' narratives, the relationship with health professionals is attended to. Such narratives are distinguishable between those which are harmonious due to their emotionality by nurses and those which capitulate to a debilitating script which manifests for parents, in confusion, uncertainty and dissociation from health professionals. These particular relationships as formed on an infant's care pathway towards the end of life provide either opportunities for coping with grief or of an emotional distancing and thus, exclusion.

#### **Domains: Perceived care**

Parents identified several domains which were deemed to be highly salient and influential to the care received prior to and around the time of the death of the infant. These included relationship building, demonstration of effort and competence, information exchange and level of parental involvement. Parents also identified coordination of care of both infant and parents as an important domain. The characteristics of both nurses and clinicians which were regarded as being the most harmful included breaking bad news in an insensitive manner, being disrespectful, withholding and an arrogant attitude.

Where a relationship with the family was forged, a sense of trust permeated throughout the relationship between parents and health professionals. Omitting to

establish such trust had deleterious consequences for parents, particularly around the time of death.

**Domains:**

**For example,**

**Relationship building – the nurse**

“Somehow she just knew what to say, what to do. She even brought in things for Jacob (first son). It’s just sweet little gestures. I will never ever, ever forget her kindness. Another day another nurse and she didn’t have that nature...”

Sara, mother of baby boy Jack (born at 39 weeks, lived for 14 days).

“On that Father’s Day when I went in there, there was even a bar of chocolate to Daddy from Ollie (baby who later died). It was little things like that, that shows they they... Even the nurses said, this isn’t like another baby that comes and goes, it affects us..”

Jim, father of baby boy Ollie (born at 39 weeks lived for 10 days)

This account lends particular insight to professional practices since there is a sense of meaning attached to a child who is personified. In this dialogic exchange, the act is significant since it has served to acknowledge the parent as a father to that child, his son. It is a status he was unable to claim more socially, in his community I later learnt in interviewing him. Yet, what remained entrenched in this fathers’ memory, and what struck me is listening back to this transcript, was a professional vulnerability and a reminder of the enormity and difficulty of this work. Their tasks it has been shown are medical, social as well as emotional.

**Demonstration of effort and competence domain**

Yet, professional support for parents is varying, with some respondents noting a particular lack of empathy which caused a great deal of distress.

“How to describe it..it was just awful. This guy arrived and said: ‘Oh, I don’t normally do scans, I’m not sure if I’m looking at the baby’s heart or not.’ I’m thinking are you the first person to arrive in this emergency and you do not know what you’re doing? It was a reg (registrar). I thought what are you doing here then? It makes you feel really angry. For a long time I felt like piece of meat on a butcher’s block. Oh well, this is an emergency who wants to do it then?”

Paula, mother of baby girl Beth (born at forty weeks, lived for two days)

This account demonstrates an emergency situation worsened by the manner by which it was responded to. It has particular consequences since it continues to anger the respondent several years after the death.

### **Information exchange**

Issues around competence overlapped with the domain of information exchange when it was perceived that consultants did not know they were doing yet, were in fact biding their time as in this particular case (information exchange). Heree the father is reflecting on his own version of events with a consultant who he perceives was reluctant to give him bad news, a task which is a part of his professional role.

R: I went to see him in SCBU with all the lines and I asked if he would make a recovery. The Consultant Paediatrician said: ‘yeah, yeah’ he can make a recovery. He didn’t give too much of an impression that there was anything too badly wrong. As time went on over the next few days we knew he was poorly and we asked if he would make a full recovery. The Consultant kept saying: ‘I can’t tell’. I said theoretically can a baby this poorly make a recovery, he said in theory yes, but I think he knew right from the start how bad it was but he didn’t want to tell us there and then so he waited until he was absolutely certain himself before he told us the bad news.....

Andy, father of baby boy Ollie (born at forty weeks, lived for twelve days).

Andy was clearly aware of his son’s deteriorating health which was not at first acknowledged by the consultant who was waiting for the right moment or biding his

time? Then we have the growing sense of disbelief. It was this sense of disbelief and ensuing confusion that led this father to search for the cause of death for which there was no previous indication.

The father's idea that advanced clinical skills and improvements in medical diagnostics could indicate the cause of death (post mortems), which more importantly provides a reason and meaning was also challenged. Up to 60 % of perinatal post mortems are inconclusive, which has consequences for parents years after the event (SANDS, 2009). For example, respondents narratives concerning inconclusive results led to continuous self-interrogation and self-blame with the majority stating: "*what if I had done this or that.*"

While Andy didn't get the answers he was looking for, he felt the level of parental involvement provided as good an ending as he could get:

#### **Level of parental involvement –**

*" We wanted to go outside when they did it ... and they were great and they put him in a pram. We went outside in the wooded area and one nurse came with us. She wandered off and just kept an eye on us. He (baby) died in our arms. You know of all the ways he could go that was as good it could get really. It was the first time we'd held him without all the tubes. He just looked like an ordinary baby and he looked like he was asleep..."*

*( Mike, father of baby boy Isaac (lived for 12 days)*

This compares with another parent whose subsequent pregnancy and birth exposed a paucity of coordination of care and also a lack of understanding the impact of subsequent births following a previous death.

*" There was a grandmother who was saying: oh you have a lovely son" and I had lost a son and I was holding my daughter. I couldn't breathe I had to get out and discharged myself and got a taxi. Not one midwife came to see how I was doing or coping because this was hard but they knew..."*

*(Mother of baby Stan, stillborn 38 weeks)*

This account along with other negative accounts when compared with more positive accounts of domains demonstrates how institutional practices are inextricably linked to emotional management in that they are embedded in the language and actions of

these particular actors. These interactions can be seen as rituals and exchanges which mobilise empathic practices or deny them. While for some they serve to acknowledge the enormity of the loss for some parents, this compares with instances even within the same hospital, where they do not.

These varying practices extend to policies and guidelines in particular and while organisations such as SANDS have developed a series of guidelines, it remains unclear the extent to which they are implemented more widely. What I suggest is that there is a real scope and a need to formalise a perinatal death care pathway which espouses that of Principle 3 of the UK Department of Health national guidelines which is to ***promote the ideal of a family centred philosophy of care on the neo natal unit to assist parents to cope with the anxiety and altered parenting roles which accompany the baby's condition (Department of health, 2009).***

The emphasis here is on the psychosocial needs of the baby and family in addition to the physical care. Similarly, the World Health Organisation (1998) defines paediatric palliative care as the total active care of the body, mind and spirit to include support to the family.

These principles set out the psychosocial and extend to both engaging and involving families and professionals on a care pathway. Further, that the examples of perinatal hospices in which both babies who are expected to die during or soon after birth enter a care pathway which include the whole family.

## **Conclusion**

The death of an infant is an extremely painful loss for parents to live with. This research suggests that the care received by parents during the hospitalisation of their child and around the time of their death can have a profound impact upon their experience of care. This critical time needs to be handled sensitively with the focus on the needs of the family and infant and in supporting staff to provide such care.

The positive domains as perceived by parents are areas for clinicians to recognise and monitor in their communication with families in the neo natal intensive care unit. Communication is highly valued by parents and has the potential to lead to sensitive communication around difficult decisions faced by clinicians and parents of infants who will be born dead or soon will.