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Title: Support and Critical Communication in the Parental Perinatal Death Experience

The death of a child on the neonatal ward represents for many parents, an unexpected and challenging event.

In this presentation I will discuss some of these experiences by parents following interviews and focus groups with thirty men and women in the UK. Parental narratives demonstrate that communication and positive psychosocial approaches forged by health professionals mediate parental responses to their infant's death. A vital aspect of this approach is the recognition of the significance of the death. While such deaths also represent a challenge to professionals, this is a time in which there is an opportunity to forge a trusting relationship even if temporary in order to provide optimal care for families following a death on NICU.

Despite advances in technology and treatment in England, sixty percent of infants occur during the first twenty eight weeks of life affecting many families (DOH, 2009). The UK DOH through their Baby Charter Standards promote the ideal of a family centred philosophy of care to assist parents to cope a guide supported by Bliss an organisation founded to support parents and babies (DOH, 2009). Similarly several guidelines including those from SANDS (2008) have been developed and promote information sharing, decision making and practices and principles which are globally relevant including as they do the total care of the infant and family. It was this aspect in the context of relationships with health professionals I was interested in as part of a larger study.

Methodology

In drawing on parents experiences, a voice centred relational method was employed to analyse data. The method as framed by Brown and Gilligan at Harvard (1993) and later by Mauthner and Doucet (1998). The method emphasises the notion of relational ontology which permits an exploration of parent's narratives in light of the relationships to people and to the broader social, structural and cultural contexts within which they live and how this impacts on their life following death.

Transcripts from interviews were read at least four times to capture these differing contexts. The third set of narratives concerned relationships and interactions with health professionals. These narratives could be compared by the care approaches to parents and which manifested in uncertainty and dissociation or were deemed far more harmonious.

These particular relationships then as formed on an infant's care pathway towards the end of life provide either opportunities for coping or of a distancing and sense of exclusion.

Results

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 their baby. These included relationship building, demonstrating effort [emotional labour], information exchange and level of parental involvement. Parents also identified co-ordination of care of both infant and parents as important. The characteristics of both clinicians which were regarded as the most harmful included breaking bad news in what was perceived as insensitive and failing to acknowledge the enormity of the loss. Conversely, where a depth of relationship had been forged between parents and clinicians, a sense of positive care had been perceived.

Domains

In this discussion concerning domains, I turn to relationship building and share with you part of a transcript by a mother whose son died two weeks after he was born. She is describing two consultants who attended her with very different approaches:

Relationship building

“The Consultant Paediatrician and the consultant Obstetrician both came to see us , to talk to us, and um they were about as different as chalk and cheese really. One had a very different world view and um he was willing to say we just don’t know what happened we can’t understand it and we’re so sorry, we just don’t know basically. He also went further than that and said: **‘Some people have a hundred years to live and some people have a fraction of a second who is to say which life is the more important.’** An amazing thing to say at the time.

The other [second consultant], he just couldn’t admit that we couldn’t resuscitate him and he was saying: **‘there’ll be a reason and um we’ll find out what it was. And if we hadn’t have resuscitated him for that amount of time he would have had brain damage, it’s probably for the best. It’s probably better that he died.’** Those were what his words were and um, I just withdrew inwardly and thought just go away It was very defensive anyway, his kind of attitude. So I wasn’t very impressed with him.....

Wynnie, mother of baby boy Jack (2 weeks old).

This account lends particular insight as to the benefit of a sensitive approach and which is evoked in memory with a sense of fondness, the extent to which this mother specifically asked the consultant to deliver her second subsequent child. I think we get a sense of the impact of the approach by the second consultant who was grappling with trying to find a cause and a reason and which reflected his own sense of unease at the situation.

Demonstration of effort

What was becoming apparent was that professional support for parents did vary with some parents perceiving a lack of empathy, namely in personifying a child which caused distress,

“I wish a really kind staff member had come in and said your baby is really beautiful, just someone to be compassionate towards her and to have treated her as a human being instead of as someone who was going to die. They didn’t at any point refer to her like she had been a human being. She was though and she was our daughter and our baby and what we hoped would be a life and there was no acknowledgement of that.....”

Laura, mother of baby girl, Rosie (10 days)

Other narratives have pointed to a reluctance to engage with parents while other staff working on other days engage more readily with parents.

It was Father’s day. That Neonatal unit I can’t fault them. On that Father’s Day when I went in there was even a bar of chocolate to Daddy from Ollie [baby who later died]. It was little things like that, that shows that they Even the nurses there said this isn’t like - ‘this isn’t another baby that comes and goes - it affects us.’

Dave, father of baby boy Sam (twelve days old).

This account lends particular insight to professional responses to loss. Of note is the sense of meaning attached to a child since his death is felt more widely and has touched professionals. This dialogic exchange between a respondent and health professional is crucial since the respondent is acknowledged as a father to this child, a status which he is unable to claim more socially when he leaves the hospital without his son. This account has also shown a sense of professional vulnerability which reveals the enormity and difficulty some nurses have in conducting work in the neonatal unit. These tasks are social, emotional as well as medical and employed in varying situations.

Information Exchange

When talking about information exchange and being told the bad news this is often a site of particular reflection for parents. In particular the following account demonstrates the struggle in trying to make sense of events, to get answers.

“ I went to see him in NICU with all the lines and asked if he would make a recovery. My first son had experienced problems and he is ok. The consultant said: ‘yeah, yeah’. He didn’t give much of an impression that there was anything badly wrong. Over the next few days we knew he was poorly and we asked again if he would make a full recovery. The consultant then kept saying: ‘I can’t tell.’ I said in theory can a baby this poorly? He said: ‘in theory, yes.’ I think he knew right from the start how bad it was but he didn’t want to tell us there and then.’

Shaun father of baby boy Rowan (10 days old)

There is a real awareness by this parent of his son’s deteriorating health which the consultant was unable to share. As this father went on to say, it was as though the consultant was biding his time. Father is also desperate for answers and hopes they are good ones, but there are none which adds to his sense of confusion because there was no known cause of death either.

Parental involvement

This account demonstrates that for some parents the level of knowledge they are seeking. They want to be informed, prepared as well as involved. And this can be achieved with the death itself. The following narrative by two mothers describe the level of parental involvement at the time of death and which served to create poignant memories:

“He died with just the two of us. Um, and we had this sort of you hold, him, you hold him. He was obviously dying as there was a great gasping for breath. This

junior doctor and a nurse kept popping in and we had some wonderful nurses and they were so special. In the end I think he died in my arms which is in that photo [points to mantelpiece].”

Mary, mother of baby boy Tom (four days old).

The rituals surrounding death were also important for parents and being able and encouraged to engage in them. In the following narrative it clearly was a treasured time:

“It was lovely up there [bereavement suite]. I bathed him and dressed him. It sounds really odd but it was the loveliest thing to be able to do to give him a bath and to get him dressed as you would any other baby. There are some nice memories from that point of view. My abiding memory was the time I spent with him, which was a lovely time, well as lovely as it can be.....”

Susie, mother of baby boy Billy (born at thirty-eight weeks, lived for nine hours).

This account together with the more positive discussion 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 at times mobilise empathic and sensitive practices which serve to acknowledge the enormity of the loss. Yet, this compares with instances even within the same hospital where they do not. In many respects clinicians may not have signed up for this. And this work can be emotionally challenging.

To engage in emotion well people turn to their emotional intelligence to process emotionally laden information competently which has been demonstrated in some instances here.

Conclusion

To that end, the death of an infant is an extremely painful loss and one which may have been unanticipated. The care then received at such a critical time can have a profound impact upon parental experiences. Yet, we know this is a time that needs to be handled sensitively, but it

isn't always. The focus of needs not only on that of the family and infant but also in supporting staff to provide such care.

The positive domains identified by parents can be areas for clinicians to recognise and monitor in their communication with families in the NICU. Because communication is highly valued by parents and has the potential to lead to sensitive and well handled encounters around difficult decisions at the end of an infant's life.

Thank you

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Little Footprints