

# End of life and bereavement care on a tertiary neonatal unit: a parental survey



**Fauzia Paize**

Consultant Neonatologist,  
Liverpool Women's NHS  
Foundation Trust  
Fauzia.paize@lwh.nhs.uk



**Jessica MacWilliam**

Paediatric Registrar, Liverpool  
Women's NHS Foundation Trust  
jessicamacwilliam@nhs.net

**Abstract:** This article reports on a small qualitative review of the impact on families when a baby dies on a neonatal unit. The study aim was to see how the service that is provided in a tertiary neonatal unit could be improved in order to help others in the same situation. This led to me carrying out a postal survey of parents who had had a baby die on the neonatal unit at the Liverpool Women's Hospital in order to gain insight into the care they received and focus on continuing the good aspects of care while improving the areas that needed some work. To maintain high standards of care reviews of practice must happen to encourage a culture of learning and feedback.

**Keywords:** neonatal, death, baby loss, prenatal, bereavement, end-of-life, palliative

## Background

I have so often seen that the hospitalisation of a newborn in a neonatal intensive care unit (NICU) is a stressful event for parents (De Rouck & Leys, 2009). Parents experience high levels of anxiety, distress and depression compared with parents with a healthy baby (Obeidat, Bond, & Callister, 2009). In addition to this, if their baby goes on to die, the experience is an incredibly painful event for parents and can affect them in the long term (Leon, 1992). It is without question one of the most distressing experiences of bereavement with long-lasting impact for bereaved parents and healthcare professionals. The news that a baby will not survive brings with it an array of emotional distress where birth and death occur in the same space and parents move from a trajectory of expectations for their life ahead to one of grief and loss. When a family experiences such a loss there is no opportunity to plan or prepare for the death. Perinatal loss is a unique type of bereavement as it disrupts a significant life milestone (pregnancy/birth/infancy) and can cause isolation from peers, inner conflict for the griever and a reorganised sense of self-esteem (Leon, 1992). Parents receive support

from various sources such as family, friends, colleagues and health professionals. How parents are cared for during this time can have long-lasting consequences, both positive and negative (Brosig, Pierucci, Kupst, & Leuthner, 2007; Williams, Munson, Zupancic, & Kirpalani, 2008).

The level of care that parents receive around the time of death has a great impact on the adjustment process and wellbeing of the parents in the long-term (Henley & Schott, 2008). In cases of sudden and unexpected death the initial care can determine the course of bereavement. In this context it has been shown that professionals need to acknowledge that parents want to say goodbye to their baby, receive information about the cause of death and feel supported by professionals (Garstang, Griffiths, & Sidebotham, 2014). Parents value health professionals and other members of their support network who approach them with sensitivity, empathy, kindness and respect. They also value professionals when they listen and communicate well and offer support before and after the death of their baby (Henley & Schott, 2008; Garstang et al., 2014; Aho, Tarkka, Astedt-Kurki, & Kaunonen, 2009) and also to the extended family such as siblings (Wender, 2012).

The Liverpool Women's Hospital looks after approximately 1,400 sick and pre-term babies every year. This leads to a significant number of deaths every year. I have seen that the toll on these families is immense and can affect their future mental health which is why we at the Liverpool Women's NHS Foundation Trust felt it was so important to evaluate this area. Evaluating healthcare quality is complex and challenging and the area of baby loss in particular is a difficult area to broach to gain insightful opinions from parents that have experienced such a devastating loss. The objective of this study was to review the personal impact of neonatal death on parents from a large level three neonatal unit in the UK

## Methods

A feedback questionnaire was sent to all parents who had a baby die on the neonatal unit from January 2010 to December 2015. These were identified through the neonatal unit electronic patient record. Two weeks before sending out the questionnaire parents were sent a letter stating that they were going to be contacted in a written format about their time at the Liverpool Women's NHS Foundation Trust. They were informed in the letter of the purpose of the questionnaire and that they were under no obligation to take part. Questionnaires were fully anonymous and consisted of 27 single response questions (yes/no/unsure) with the opportunity to provide free text comments.

## Results

A total of 86 questionnaires were sent out. There were three incorrect addresses, as the individuals had moved. 26 questionnaires were returned – a response rate of 30.2%.

### Communication from staff

The majority of respondents felt they were given enough information from doctors (94%) and nursing staff (87%) while their baby was on the unit.

*'We were well informed prior to her being born and it felt that staff was cautiously optimistic which worked well enough for us. At the same time we were under no illusions about the risks.'*

*'Our baby didn't spend a long time on the unit as he only lived for a day and a half but we later found out that his condition started deteriorating quite a while before we were told – if we'd known earlier we would have spent more time with him.'*

### Involvement in care

Eighty one per cent of respondents felt they were involved in their baby's care whilst they were on the unit. Of those

who did not feel involved, the rapid deterioration of their child was given as a reason for this.

*'We were aware of what was being done for her but she was only ill for a short time so we didn't have a great deal of involvement in her care for that reason.'*

*'I got to hold him as he died and that is so important.'*

*'Maria had major surgery for NEC [necrotizing enterocolitis] the week before she died and so it was difficult to be completely involved with her care after her surgery. However the nurses and staff made sure that we could be as close as possible and have valuable family time, even though she was very poorly.'*

### Time and privacy with baby

Only 75% of respondents felt they had enough time and privacy with their baby before they died. Those who didn't commented on speed of deterioration and busyness of the unit as an obstacle to this. Many respondents commented on the importance of having the opportunity to hold their baby; those who felt they had not had enough time with them commented that they would have liked more cuddle time.

*'It all happened very quickly but yes we were given as much time as we needed and lots of privacy.'*

*'We do wish that we could have had more skin to skin time with her in the time prior to her surgery but understand that the unit is very busy and time isn't always available. We did spend as much time as we could at her cotside and reading to her. As a mum expressing throughout the day, time management is a struggle, so it can be hard to get the alone time with the baby.'*

*'I feel like we were rushed to make a decision about switching off his ventilator as we were told that his condition could deteriorate very quickly. However the doctors provided further tests when we asked for them to help us make an informed decision. I would have liked to have held my son more than once and understand that I had longer with him.'*

### Choosing where baby died

Fifty six percent of respondents were able to choose where their baby died. Many of those who didn't stated rapid deterioration as a reason for this. Several respondents commented on the importance of being able to hold or have contact with their baby when they died.

*'I don't think we were, everything happened very quickly and I don't imagine that would have given us any choice. Plus she seemed to be in the best place to give her the best chance.'*

*'We didn't know at the time that there was ever any choice.'*

*'When Jacob's blood was dropping and I made the decision to turn off the machines I wasn't given a choice in where to go. I got placed in a bereavement room where Jacob passed away in my arms.'*

## Offer of spiritual support before baby's death

Ninety four per cent of respondents were offered spiritual support such as baptism. Rapid deterioration was stated as a reason why those who didn't did not get this opportunity.

*'We met with the chaplain but only after she had passed. Again I doubt there would have been any time before.'*

*'We were offered for the chaplain to baptise him but we declined – in hindsight I wished we'd said yes if only it would've meant we got more time with him before he died.'*

*'Maria was blessed the night that she died as the hospital arranged for Father to come and see us all in one of the private rooms. Although this was after she had passed, it was still a great comfort. The time that we had in the unit with her following her death was so important to us and we never felt rushed or in the way.'*

## Box of keepsakes

All respondents received a box of keepsakes and 94% of those felt this was helpful. Of those who did not find this useful the only comment was that they found it too hard to look in the box currently.

*'Yes I love to look through it.'*

*'That box is amongst my most treasured possession.'*

*'The keepsake box was extremely helpful and comforting. It is something that we will always treasure.'*

*'The box is still something I look at daily, often holding his blanket and hat. It is one of the only things that proves my baby existed, something I cherish greatly.'*

## Registration of baby's death

Eighty seven per cent of respondents stated that they were given information regarding their baby's death and that this information was helpful. 56% of respondents had to register the death of their baby at the same time as parents routinely registering their baby's birth; those who did found this understandably upsetting.

*'I feel we felt proud to be able to register her birth and it was reassuring for us to be able to do that. For us there was no issue in registering death at the same time as people do births but perhaps there could be some consideration to offering specific time slots or flexibility to people who have lost babies.'*

*'This was particularly hard for us, as we had only been in the office to register her birth a few weeks previous. As the office is within the hospital there had been a number of parents waiting to register their baby and this made it more difficult. It would help if births and death could be separated but we understood that it's not always possible.'*

*'I found it very difficult sitting in the same room as a couple with their living baby while I waited to register both birth and death of my twins. I feel this should be separately done as the pain is severe enough at the time.'*

## Funeral options

Seventy five per cent of respondents had funeral options discussed with them, with 44% receiving written information around the subject. Written feedback indicates that the face-to-face communication with the bereavement team was very important to those parents who required assistance with funeral options.

Parental quotes from free text:

*'We wanted and felt able to do it ourselves but welcomed the info that was shared that meant we felt able to do it ourselves.'*

*'Help with funeral arrangements was patchy and there wasn't always someone around in the office, but they were very nice and helpful when we did see them. This was just prior to the creation of the Honeysuckle Team and I understand that it is much better co-ordinated now.'*

## Follow-up appointment

Seventy five per cent of respondents returned to the hospital for a follow-up appointment with their baby's consultant.

Seventy five per cent of those who attended an appointment found it useful. 94% of those respondents whose babies had a post mortem had the results of this available for this appointment and written feedback indicated that it was information from the post mortem that parents found the most useful, if upsetting at these appointments.

*'We had an appointment with our son's consultant and a consultant obstetrician. Our son's neonatologist was helpful as we could find out the details of his short life and illness but the obstetrician didn't provide any information and we felt he was quite offhand about it, ie.twins are premature all the time, it's one of those things etc – unhelpful and upsetting.'*

*'The appointment was really helpful in understanding what our baby had been through, if anything else could have been done to save him and test results implications on future children/pregnancies.'*

## Ongoing support

Sixty nine per cent of respondents received additional support from their GP, a counsellor or bereavement services, although 56% of respondents would have liked more long-term support.

*'My GP telephoned me at the hospital after our second twin's birth and was very sympathetic. Our health visitor came to visit when our second twin got to low dependency and was a great support to me for many months as was my GP.'*

*'I had counselling that helped, but I am left with anger still which I find hard to deal with at times.'*

*'I didn't feel I needed support long-term and I know I can access that myself as I'm confident enough to do so. However, I carry a lot of anxiety about becoming pregnant again, I feel I can manage this but I feel there should be more mental health and emotional support to families in the long term as it can be a very isolating experience as well as people are reluctant to talk about infant loss, still birth etc.'*

## Discussion

The results of this study provide much needed insight into parents' information and communication needs in neonatal end-of-life situations in the NICU and during bereavement in order to influence future care for these families. The feedback received from parents is in keeping with existing knowledge around what aspects of care are important to families who have a baby on the neonatal unit (Shelkowitz, Vessella, O'Reilly, Tucker, & Lechner,

2015; Mancini, 2012), most notably the importance of memory making and families having the opportunity to spend time with their baby. A memory box is a helpful tool in ensuring families have keepsakes to help them remember their baby. Activities such as holding, bathing and dressing the baby, gaining hand and footprint casts of their baby, engaging in religious or naming ceremonies, introducing the baby to extended family, talking to the baby and using the baby's name and capturing interactions in photographs and movies should be supported. Parents should be offered items such as photos and special clothing or blankets when a baby dies.

Choice of where their baby can die, for example at a hospice, should also be offered if possible. Families are not always aware of these options and this been recognised as an important element of end-of-life planning (Janvier, Farlow, Verhagen, & Barrington, 2017; Together for Short Lives, 2017). Staff should always provide objective information in a calm, supportive manner, while balancing guidance with parental autonomy. Critical information should be repeated and reinforced with written materials. Communication is vital in ensuring that families have the least traumatic experience possible and are aware that everything possible has been done for their child (Wender, 2012). This includes ensuring that all parents are aware that they have the opportunity to have cuddles with their baby while they are on the unit, regardless of whether they are heading towards the end of life, as this is good parallel planning (Together for Short Lives, 2017). There is a need to continue developing a compassionate approach towards communicating with these families. Professionals can play an important role in reversing stigma and social attitudes surrounding neonatal death via communicating directly with parents but also by publishing work in this area and in the training of future clinicians.

Bereavement care has changed over time from parents not being allowed to talk about their deceased child, to see their child after death or to show their grief, to a greater understanding of the loss and pain parents experience after the death of their child baby (Henley & Schott, 2008; Garstang et al., 2014; Aho et al., 2009; Koopmans, Wilson, Cacciatore, & Flenady, 2013). Although this has changed the way in which support is provided to the family, parents in this study have asked for ways to optimise family support. Healthcare workers should offer support repeatedly and provide parents with written and verbal information about the grieving process and options for support. In keeping with the findings of other studies, parents indicate that they would appreciate the provision of more support and follow-up appointments and contacts with a professional after the death of their child (Garstang et al., 2014; Aho et al., 2009; McHaffie, Laing, & Lloyd, 2001). Grief has clinical features that are similar to clinical depression and can be very pronounced in parents who have lost a baby. Symptoms of anxiety and depression in



parents who experience neonatal death can persist more than a year (Vance, Boyle, Najman, & Thearle, 2002). Although grief and depression are not the same, screening for depression or very high levels of grief in the first few months after a child's death may help identify parents at risk of unresolved or complicated grief (Hutti et al., 2018). Improvements are needed for mental health support and counselling beyond the brief period of hospitalisation and research is needed to evaluate particular interventions and practices that take into account cultural variation among patient populations. For healthcare professionals generally it should be noted that follow-up phone calls and appointments are vital and have been shown to be considered highly important (Wender, 2012; McHaffie et al., 2001; Boyle, Mutch, Barber, Carroll, & Dean, 2015).

Feedback regarding parental experiences of registering the death of their child highlights how better communication between departments and better care pathways could improve patient experience. Parents who are registering the death of their child are now given appointments with the registrar at a time when there are no other parents expected or they are allowed to wait in a different place so they are not having to wait with parents who are registering a birth. This is a significant service improvement that has been made in light of these findings and should be promoted elsewhere.

Studies have shown that both nurses and doctors feel under-prepared to have conversations with families regarding end-of-life and bereavement issues (Engler et al., 2004). All healthcare providers in this setting need to receive training to ensure that they are able to provide appropriate care following a perinatal death. Additionally, staff confronted with such losses need to be supported via the debriefing process and be offered psychological support themselves if needed. Staff working with families facing or experiencing a perinatal bereavement must be trained on how to work with families under this level of stress and how to have difficult conversations

## Conclusions

The quotes from this work clearly show the impact on families of neonatal death. All units should continue to provide a level of service that is in line with published guidance and need to consider ways in which they can provide long-term support for families and also facilitate the opportunities for families to spend time together and make memories. The vital importance of service evaluation and a constant cycle of improvement cannot be over-emphasised. ■

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