

Butterfly Project: supporting parents who have lost a baby from a multiple pregnancy



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Rigorously conducted, in-depth qualitative research can identify ways in which healthcare professionals can have positive and long lasting impacts on parents who are suffering the trauma of reproductive loss. Identifying behaviours and actions that are both positive and negative is an important first step in translating research into practice, and improving staff education with the aim of improving the experiences of families and the staff who care for them.

Infant readers will be familiar with two previous articles describing the process that healthcare professionals and research staff at Newcastle Neonatal Service and Newcastle University have used to develop guidelines and improve support for parents who have suffered the loss of a baby from a multiple (eg twin) pregnancy. In the first article, we presented the results of a scoping exercise where we explored the availability of existing resources that could be used to support staff education and training.¹ In the second, we described the process for developing a guideline and other supporting resources based on translating our in-depth qualitative research of parent and staff views and experiences on the topic.² This Focus article looks at the development of the Butterfly Project, discussing recent feedback from parents, support groups and health professionals and reviewing the resources that are available for staff and parents in the area of reproductive loss.

Key themes

Although parents were very positive about the medical care their surviving baby had received, our research identified a number of recurring themes, especially from parents about their experience with healthcare professionals with examples of positive and negative behaviours, actions and words.^{3,4} To develop the resources, we focused on eight key themes (TABLE 1) although it is important to highlight this is not a comprehensive list of all the issues that were identified.

Butterfly cot cards

One of the key themes that emerged concerned recognition of twin status. Parents told us they frequently had to retell their painful stories. This was of particular concern during nursing or medical shift handovers when staff had not met the family before but also occurred where there was involvement of more than one healthcare team (eg primary and secondary care, fetal medicine, special care baby unit, etc). While parents frequently wanted to talk about the baby who had died, they quite understandably felt that the information should have been available in their healthcare records

and staff should hand over details between and within teams.

A failure to recognise or acknowledge that a surviving baby was a twin, especially on special care baby units or in other healthcare settings (eg antenatal clinics), caused many parents considerable distress. In our 2014 workshop sessions, the idea of using a symbol to identify surviving babies emerged, which we developed in 2015 as a butterfly cot card (FIGURE 1). This card can be placed on the incubator or crib, or on a nearby wall. We offer parents the opportunity of writing the name of the baby who died on the butterfly cot card itself, although we recognise that some of the babies may have been lost at an early stage of pregnancy before they were named.

It is vital that the process of adopting a butterfly symbol is discussed with parents so they understand that its use is entirely their choice, but also that it will visibly identify their baby as being unique to all staff, parents and other visitors. Some parents may prefer that their loss is not available for others to see, while at the same time expecting that healthcare professionals are aware of

Theme	Brief description
Recognise twin status	Parents generally appreciate it when staff recognise that their surviving baby is a twin
Acknowledge the bereavement	Parents usually welcome the opportunity to discuss the loss of the twin who died
Provide emotional support	Parents value the empathy they receive from staff when one of their twins dies
Provide appropriate information	It is very important to give parents access to information on an ongoing basis
Provide continuity	Parents appreciate continuity of care where possible and seeing familiar faces
Offer memory making	Parents find comfort in mementos of both of their twins
Handle cot occupancy sensitively on the neonatal unit	It can be painful for parents who have lost a twin to be surrounded by other twins
Prepare parents for discharge from hospital	Parents can find the discharge from hospital of their surviving twin difficult

TABLE 1 The key themes generated by the qualitative research project² identifying ways in which staff can support parents who have suffered the loss of a baby from a multiple pregnancy.

their experience. We also considered using smaller butterfly stickers for medical notes and records, although these will require approval from individual hospital trusts before they can be placed on medical records. However, we found that they could be used on handheld maternity records or child health records. Butterfly cot cards are available on our website (www.neonatalresearch.net/butterfly_project).

Feedback from parents

During the initial roll-out period in 2015, we did not collect routine feedback from parents. However, our local experience is that all parents suffering such a loss have chosen to use the butterfly symbol and anecdotally all parents said they felt it was helpful. In addition, staff have said they appreciate the reminder of twin status and felt more able to discuss the loss with parents. A mother told us:

“Losing Baby-J when he was just a few days old was almost unbearable... this was even worse because Baby-D was still very sick... we didn't know what to say or do. We liked the idea of a butterfly cot card and being able to write Baby-J's name on it. We know the [butterfly] cot card is only a symbol, but it helps remind everyone Baby-D is a twin... it has made it easier for us to talk about Baby-J with the nurses.”

We are now planning a more formal evaluation of parent experiences of the butterfly cot card using a mixed methods approach.

Questionnaire survey

We developed a brief questionnaire to assess staff confidence and expertise in this area and the existence of current guidelines. This was cascaded via managed clinical networks, professional organisations and support groups and has so far received over 350 responses representing more than 100 hospitals from across the UK. We are currently analysing the data and will publish this shortly. Our guidelines have been shared with approximately 60 hospitals so far and we have distributed more than 800 butterfly cot cards. In addition, we received interest from other countries including North and South America, and Europe, as well as a request to translate the guidelines into other languages. This is a challenging task, not least because of socio-cultural language differences and the impossibility of directly translating parental quotes. We have, however, successfully translated the guideline into Spanish with the help of clinicians in Argentina and Europe and plan to attempt further languages over the next 12 months.

Resources

With generous funding from the charity Tiny Lives (www.tinylives.org.uk) and the Academic Health Sciences Network North East and North Cumbria we developed three resources that are currently available on our website:

1. Guideline – this summarises practical advice for staff to support parents and the positive behaviours and actions that can be adopted.
2. Teaching slides – a series of powerpoint slides with quotes from parents and staff that exemplify the key themes. This could be used to facilitate a staff education session.
3. Leaflet – a very brief summary of the eight key themes that could be provided at a teaching update session for staff to retain. Other organisations produce resources for helping to cope with loss and bereavement for parents, for example:



FIGURE 1 The butterfly cot card (arrow) next to an incubator on the special care baby unit. Above: The butterfly cot card with space for the baby's name.

- European Foundation for the Care of Newborn Infants (www.efcni.org)
- Twins and Multiple Births Association (www.tamba.org.uk)
- Multiple Births Foundation (www.multiplebirths.org.uk)
- Child Bereavement UK (www.childbereavementuk.org)

We also identified a children's book specifically for families who have lost a twin. The author, Kate Polley, wrote the *Sam and Finn* book to share Sam's story with her surviving premature twin Finn. The names in the book can be personalised for parents to help them discuss the loss with the surviving or other siblings (see Book Reviews on page 218).

Future directions

Our focus has been on developing resources to inform and better educate healthcare professionals, but we are aware of the importance of providing direct support to parents. Anecdotally, we have observed that the use of a butterfly symbol has helped parents discuss their feelings more openly with staff and also to attempt to tackle the taboo associated with reproductive loss, which includes miscarriage, stillbirth and neonatal loss. Nevertheless, we feel that parents may also benefit from specific resources although these are likely to be highly individual.

We are aware that our written guidelines are necessarily quite lengthy and that delivering a teaching session where a facilitator 'speaks' for parents will always be less powerful and engaging than hearing parents directly. With this in mind, we are working with charity groups to develop a short film made with parents who have suffered such losses speaking directly about their experiences. This would be produced with the intention of making it freely available across the NHS.

References

1. Crowe L, Embleton N.D., Rankin J. Investigating available resources on loss from a multiple pregnancy to inform practice. *Infant* 2015;11:123-26.
2. Hayes L, Richards J, Crowe L et al. Development of guidelines for health professionals supporting parents who have lost a baby from a multiple pregnancy. *Infant* 2015;11:164-66.
3. Richards J, Graham R., Embleton N.D. et al. Mother's perspectives on the perinatal loss of a co-twin: a qualitative study. *BMC Pregnancy Childbirth* 2015;15:143.
4. Richards J, Graham R.H., Embleton N.D., Rankin J. Health professionals' perspectives on bereavement following loss from a twin pregnancy: a qualitative study. *J Perinatol* 2016;529-32.