

Institution: Newcastle University		
Unit of Assessment: UoA 3		
Title of case study: Best practice for healthcare professionals in supporting parents who have experienced a bereavement from a multiple pregnancy		
Period when the underpinning research was undertaken: 2015-2016		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor Judith Rankin Dr Judy Richards	Principal Investigator Researcher on the original qualitative study	1993-present 2009-2020
Dr Ruth Graham	Co-author of the qualitative study and co-applicant of original funding	2011-present
Dr Louise Hayes	Researcher involved in guideline development	1995-present
Dr Lisa Crowe	Involved in phase 1 of best practice development	2014-present
Professor Nick Embleton	Consultant Neonatal Paediatrician, Newcastle upon Tyne Hospitals NHS Foundation Trust with an honorary Newcastle University contract	2002-present
Period when the claimed impact occurred: April 2016-present		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact		
<p>Compared with single births, the 11,000 multiple births every year in the UK carry a greater risk of adverse outcomes, which can include the death of one or more babies. While loss in a pregnancy at any stage is devastating, loss from a multiple pregnancy presents a specific challenge as parents are often faced with caring for surviving babies while undergoing the grieving process. Newcastle conducted extensive collaborative research with parents and healthcare professionals, and identified several important changes in practice that parents found helpful. These recommendations have informed national and international best practice, which have measurably increased clinicians' confidence in supporting parents.</p>		
2. Underpinning research		
<u>Background and unmet need</u>		
<p>In the UK, there were 11,153 multiple births in 2018, of which 11,010 were a twin birth and 143 were triplets¹. Multiple pregnancies have a greater risk of adverse outcomes, including the death of one or more babies. The death of one multiple after the first trimester (after 12 completed weeks of pregnancy) occurs in 4-8% of twin pregnancies, and in 11-17% of triplets². A Newcastle study (R1) found that neither stillbirth nor neonatal death rates from a multiple pregnancy improved over a 10-year period.</p>		
<p>While loss from a pregnancy at any stage or soon after birth is devastating for a parent, Newcastle research found that loss from a multiple pregnancy presents a specific set of issues, such as still needing to care for the surviving baby whilst coping with the bereavement; or loss of their "special status" as parents of multiples. Many hospital support services are not properly equipped to deal with these specific needs, such as being able to deliver continuity of care. In addition, healthcare professionals (HCPs) often do not know how best to offer support during this traumatic time. A 2016 Newcastle-led survey of 293 HCPs³ found that less than half had received training on supporting loss from a twin pregnancy, a third felt that current training and guidelines were inadequate and around two thirds wanted more training.</p>		

¹<http://www.multiplebirths.org.uk/media.asp>

²<http://www.climb-support.org/html/article.html?bilibis&raisingsurvivors>

³<https://doi.org/10.1186/s12884-021-03543-9>

The contributions of Newcastle research

To understand the support parents needed from HCPs, Newcastle conducted in-depth semi-structured qualitative interviews with 14 parents who had experienced a loss from a multiple pregnancy (R2). Participants stressed how highly they valued HCPs who showed sensitivity to their loss. Additionally, this study highlighted that many of the parents' needs can be met by relatively small changes, including placing a surviving twin away from healthy sets of multiples; using the names of both deceased and surviving babies; recognising the twin identity of the surviving baby; allowing parents to talk about their loss; and providing continuity of the baby's care team. These small changes in practice substantially improved parents' well-being, and the paper made recommendations for best practice.

The second study (R3) used the same methodology to interview 26 HCPs. Three common themes were found: first, in daily interactions with bereaved parents there was a fundamental difference between caring for parents who had lost a singleton compared with death from a multiple pregnancy, and that the HCPs felt less confident about addressing the emotional needs of the latter group of parents. Secondly, HCPs expressed a need for specialist training in supporting the specific emotions felt by parents in this situation. Thirdly, the practical steps outlined above were acknowledged as good practice to demonstrate sensitive care to parents. The findings from R2 and R3 were combined into practical best practice guidance (R4) using an iterative co-design approach closely involving parents and HCPs.

Finally, a key theme that emerged from the research was recognition of twin status. In the initial workshop (R2), one practical suggestion was placing a symbol on the cot indicating the baby has a deceased twin, to avoid parents having to repeatedly explain the situation. As a result, a local project (R5) printed and distributed cot cards with a purple butterfly and space to write in the deceased child's name (right). Results from R5 showed that all parents who had undergone such a bereavement chose to use a card and found it helpful. In addition, staff appreciated the reminder of twin status and felt more able to discuss the loss with parents.



The guidelines and cot cards were taken forward as the Butterfly Project (R5). Cot cards were distributed in collaboration with the Skye High Foundation, a UK charity recently established specifically to help families dealing with loss from a multiple birth.

3. References to the research

Journal rankings taken from <http://www.scimagojr.com/journalrank.php?category=2729>. Newcastle researchers in **bold**.

- R1. **Glinianaia SV, Rankin J**, Sturgiss SN, Ward Platt MP, Crowder D, **Bell R**. (2013) The North of England Survey of Twin and Multiple Pregnancy. *Twin Research and Human Genetics*. 16(1):112-6. DOI: 10.1017/thg.2012.65.
- R2. **Richards J, Graham R, Embleton ND**, Campbell C, **Rankin J**. (2015) Mothers' perspectives on the perinatal loss of a co-twin: A qualitative study. *BMC Pregnancy & Childbirth*. 15:143. DOI: 10.1186/s12884-015-0579-z. Rank: 19/173 in Obs and Gynae.
- R3. **Richards J, Graham RH, Embleton ND, Rankin J**. (2016) Health professionals' perspectives on bereavement following loss from a twin pregnancy: A qualitative study. *Journal of Perinatology*. 36(7):529-32. DOI: 10.1038/jp.2016.13. Rank: 10/173 in Obs and Gynae.
- R4. **Hayes L, Richards J, Crowe L**, Campbell C, **Embleton ND, Rankin J**. (2015) Development of guidelines for health professionals supporting parents who have lost a baby from a multiple pregnancy. *Infant*. 11(5):164-166. https://www.infantjournal.co.uk/pdf/inf_065_rof.pdf
- R5. **Embleton ND**, Stephenson S, Campbell C, **Hayes L, Richards J, Rankin J**. (2016) Butterfly Project: supporting parents who have lost a baby from a multiple pregnancy. *Infant*. 12(6):1-2. https://www.infantjournal.co.uk/pdf/inf_072_ocu.pdf

4. Details of the impact

Development of best practice guidance to help healthcare professionals support parents

The main results from R2-R4 were used to co-produce practical guidance with HCPs and parents (EV1) and were published on the Butterfly Project website (www.neonatalbutterflyproject.org) in early 2016. As at July 2020, over 700 HCPs were registered from over 25 countries, and the site receives over 10,000 hits a year (EV2). This educational site hosts short video clips illustrating the main themes, to improve understanding of this challenging situation and offering a way for HCPs to discuss the loss with the parents. The resources are available free of charge, and thanks to international demand they have been translated into more than 10 languages such as French, German, Italian, Spanish and Arabic.

Other national bodies have subsequently taken up the research to inform their own guidelines. In 2016, the national stillbirth and neonatal death charity Sands used R2 to underpin the 4th edition of their guidelines for professionals “Pregnancy loss and the death of a baby” (EV3). For example, on page 194 the guidelines state:

- “If one or more babies have already died, it is important that staff caring for the surviving baby or babies... recognise the importance of all the babies to the parents and listen when the parents want to talk about the baby or babies who have died [citing R2].”
- “Support from staff may be crucial for parents’ well-being [citing R2].”

Sands also lead the National Bereavement Care Pathway, which signposts to Butterfly Project resources from its website (EV4).

In 2017, the Twins Trust produced a bereavement booklet which provides information on the Butterfly Project on page 68 (EV5).

In addition, the research, guidelines and cot cards have been used and endorsed by the following bodies (EV6):

- In a letter signed by Cheryl Mackrory MP and the Rt Hon Jeremy Hunt, the All-Party Parliamentary Working Group on Baby Loss confirmed their full endorsement of the Butterfly Project and that it has enabled HCPs to feel more confident in supporting parents.
- Bereavement Training International, who have provided training since early 2016 to over 500 nurses, midwives and doctors. Many participants stated that this has been the most important and relevant element of the training and reported an increase in confidence when supporting parents at this very difficult time.
- The Tiny Lives Trust, who were a major sponsor of this research, stated that they fully endorse this work and that the training improves HCPs’ confidence in supporting parents.

As at July 2020, more than 10,000 cot cards have been distributed to 250 hospitals across the UK by the Skye High Foundation, who stated that “The cards have been very well received by parents, who value the kindness and support shown by hospital staff during a traumatic time” (EV7).

Impact on knowledge and confidence of healthcare professionals

A follow-up survey of HCPs (EV8) conducted in late 2019 showed that the material had improved their confidence. Of the 56 who provided responses to the question “Since completing the last survey in 2016, how confident do you feel in providing practical support and information?”, 89% reported feeling more confident. In addition, 85% said they felt that continuity of care had improved. All participants found the guidelines useful, and 71% said the guidelines better equipped staff to support parents. In terms of the Butterfly Project website, 96% found it helpful and 91% found the films helpful. In addition, 64% had used the butterfly cards and provided overwhelmingly positive feedback.

Feedback was also received from clinical leads from various Hospital Trusts in the UK (EV9), including:

- South Tees, where the guidance has been used since 2015 by over 100 HCPs.

Impact case study (REF3)

- Bradford Teaching Hospitals, where the guidance has been used since 2016 by over 100 HCPs.
- The Royal Hospital for Children, Glasgow, where the guidance has been used since January 2017 by over 150 maternity HCPs.
- University Hospital Southampton, where the guidance has been used since 2017/18 by 170 Neonatal Staff.

The guidance has also been used internationally (EV10), including:

- Hospital Moinhos de Vento, Brazil who began using the guidance in October 2018 for all 25 NICU HCPs.
- Sachs' Children and Youth Hospital, Stockholm, Sweden where it has been translated into Swedish and is used by all staff.

All units confirmed that HCPs reported an increase in confidence after the guidelines were adopted. They had also all received or produced their own cot cards, which have been well received by parents during a difficult time.

Impact on parents

In late 2020, a survey was carried out with parents who had undergone a loss from a multiple pregnancy. Participation was voluntary and parents were approached with tact and sensitivity. Of the 41 who responded, 51% had been offered a cot card and found it helpful and 23% were not offered a card but would have liked one. Other responses discussed the logistics of card distribution but were generally positive (EV2).

In summary: Newcastle research, co-produced with parents and HCPs, has led to guidance which has been widely used to best support parents during a traumatic time.

5. Sources to corroborate the impact

EV1. Bereavement from a twin pregnancy: Guidelines for health professionals 2016.

https://www.neonatalbutterflyproject.org/wp-content/uploads/2017/08/Butterfly_guidelines_English.pdf

EV2. Corroboration by Professor Nick Embleton, Consultant Neonatal Paediatrician, Newcastle upon Tyne Hospitals NHS Foundation Trust.

EV3. Pregnancy loss and the death of a baby 2016.

<https://www.sands.org.uk/professionals/bereavement-care-resources/sands-guidelines-4th-edition> or available on request.

EV4. National Bereavement Care Pathway website.

<https://nbcpathway.org.uk/professionals/shared-practice-nbcp-sites> See link under “Supporting families after loss of a baby from a twin / multiple pregnancy.”

EV5. Bereavement Support Group 2017 booklet <https://twinstrust.org/uploads/assets/1a37eb18-be5d-4b6b-83ee8af6bf19bf45/bereavement-booklet.pdf>

EV6 Letters from:

EV6a. The All-Party Parliamentary Group on Baby Loss.

EV6b. Bereavement Training International.

EV6c. Tiny Lives.

EV7. Letter from the Skye High Foundation.

EV8. Data available on request.

EV9. Letters from:

EV9a. South Tees Hospitals NHS Foundation Trust.

EV9b. Bradford Teaching Hospitals NHS Foundation Trust.

EV9c. Letter from The Royal Hospital for Children, Glasgow.

EV9d. Letter from University Hospital Southampton NHS Foundation Trust.

EV10. Letters from:

EV10a. Hospital Moinhos de Vento, Brazil.

EV10b. Sachs' Children and Youth Hospital, Stockholm, Sweden.