Development of guidelines for health professionals supporting parents who have lost a baby from a multiple pregnancy

Parents who suffer a bereavement from a multiple pregnancy experience complex emotions as they often find themselves caring for a surviving sibling while mourning the loss of their infant. It is important that they are supported by health professionals at this time. This article describes a co-design approach to the development of guidelines for health professionals who support parents that have suffered the loss of a baby from a multiple pregnancy.

Louise Hayes[1]
Research Associate

Judy Richards[1]
Research Associate

Lisa Crowe[1]
Research Associate

Claire Campbell[2]
Senior Neonatal Nurse

Nicholas D. Embleton[2]
Consultant Neonatal Paediatrician

Judith Rankin[1]
Professor of Maternal and Perinatal Epidemiology
judith.rankin@ncl.ac.uk

[1]Institute of Health and Society, Newcastle University
[2]Newcastle Neonatal Service, Royal Victoria Infirmary, Newcastle upon Tyne

Keywords

guidelines; health professionals; multiple pregnancy; bereavement; co-design

Key points

Hayes L., Richards J., Crowe L., Campbell C., Embleton N.D., Rankin J. Development of guidelines for health professionals supporting parents who have lost a baby from a multiple pregnancy. *Infant* 2015; 11(5): 164-66.

1. Health professionals have expressed a need for guidance to support parents who have experienced loss of a baby from a multiple pregnancy.
2. The involvement of health professionals and patient representatives to develop guidelines using a co-design approach, ensured they were appropriate, acceptable and met the expressed need.

This is the second of two articles on the development of guidelines for health professionals supporting parents that have suffered the loss of a baby from a multiple pregnancy. The previous paper described a process (scoping review) of searching for available resources relating to a loss from a multiple pregnancy.[1] The article presented here describes the second phase of this work; the process of developing guidelines for health professionals involved in supporting parents who have lost a baby from a multiple pregnancy. Using co-design methods to develop the guidelines, the authors worked iteratively with health professionals and parent representatives to combine the information identified in phase one of the project with specific training needs identified from interviews with staff and parents conducted in a previous qualitative study.[2]

The term multiple is used for simplicity but is understood to mean twin, triplet or higher order multiples throughout.

Introduction

When parents lose a singleton infant, or all babies from a multiple pregnancy, it is readily identified as a tragedy. However, when one infant survives the parents face a complex situation.[3] They experience mixed emotions of enormous grief for the infant who died along with hope and joy at the birth of their surviving baby. A recent in-depth qualitative study, undertaken by the authors in a partnership between Newcastle University, Newcastle upon Tyne Hospitals NHS Foundation Trust and the charity, Tiny Lives Trust, explored the views of parents and health professionals who have experience of a bereavement from a twin pregnancy. The study found that staff often felt they lacked confidence in supporting bereaved parents in this situation.[2]

The aim of this follow-on work, funded by the Academic Health Science Network (AHSN) North East and North Cumbria in partnership with the Tiny Lives Trust, was to develop guidelines for health professionals (midwives, obstetric and neonatal staff) working 'on the shop floor', as opposed to those working in formal counselling or support roles.

Methods

A co-design approach was taken to develop the guidelines. Co-design methods are increasingly used in health care to improve service delivery. These methods involve the collection and bringing together of staff and patient experiences to identify areas where improvements to services can be made.[4] Co-design methods to develop services or care pathways have increasingly been used within the NHS over the last few years, where they are often referred to as 'experience-based co-design' (EBCD).[4] EBCD aims to identify points in patients' experiences of health care that are emotionally significant to them (in both positive and negative ways) by collecting information from patients and staff using a range of qualitative methods, including in-depth interviews and focus group discussions. The involvement of both patients and staff in the process of developing services in this way helps to improve the experience that patients have.

The approach involved several iterative

stages (**FIGURE 1**). The first step was for a member of the research team (LH) to review transcripts of the interviews undertaken in the previous qualitative study.[2] Factors that were important in determining whether or not parents felt well-supported by health professionals at the time of their bereavement, and areas where health professionals felt they lacked confidence in supporting parents at this time were identified. These factors were considered to be training points, which should be captured in the resulting guidelines. Each transcript was reviewed and training points were identified and categorised into an emerging framework.

The second step reviewed the identified training points. The research team, comprising neonatal medical and nursing professionals as well as academic and research staff, agreed on the broad topic areas that the guidelines should cover. This was achieved in a face-to-face meeting of the research team. Following this meeting, one team member (LH) drafted the first version of the guidelines. This initial version was circulated to the research team for comments. These comments were discussed in a second meeting of the research team and modifications for a second draft were agreed.

The third step was to hold a co-design workshop. A total of 31 individuals (including the research team, health professionals, patient representatives and representatives from relevant patient organisations) attended the workshop. The draft guidelines were circulated to all participants prior to the workshop. Participants were split into three groups. Each group comprised a mix of different categories of staff and representatives of different organisations. At the workshop participants discussed their comments on the guidelines within the three groups and presented a collated summary of suggested changes and additions to the whole group (**FIGURE 2**).

The ethos of co-design methods is that everybody's opinion is valued and all voices should be heard. This was emphasised during the workshop and, in addition, participants were given the option of providing feedback via email after the workshop. Enthusiastic input and positive feedback from both health professionals and patient representatives involved in the process was received.

The last step in this part of the guideline development process was to revise the draft guidelines in light of the comments received from participants at, and after, the workshop. This resulted in the final version of the guidelines, which are ready for dissemination. This 'final' version will be reviewed and revised on an ongoing basis in response to users' comments.

In addition to the development of the guidelines, a short leaflet summarising the guidelines and a Powerpoint-based training session, intended to be used by one member of a team to train other members of the team, have also been produced. The guideline and teaching pack can be obtained at www.neonatalresearch.net/health-professional-feedback.html. The authors request that users complete a brief survey on supporting parents who have lost a baby from a multiple pregnancy.

Content of the guidelines

A number of behaviours and actions that staff can adopt that parents find helpful around the time of a bereavement from a multiple pregnancy were identified and refined during the process of guideline development. These are summarised as follows.

Recognise multiple status

Parents appreciated it when staff recognised that their surviving baby was a multiple and found it upsetting when it seemed to have been forgotten. One way of helping to ensure that multiple status is remembered is to use a symbol (for example a butterfly) on the surviving infant's cot to indicate to staff and other parents who have experienced a similar loss, that the baby is a multiple. This could help prevent unintentional painful comments being made.

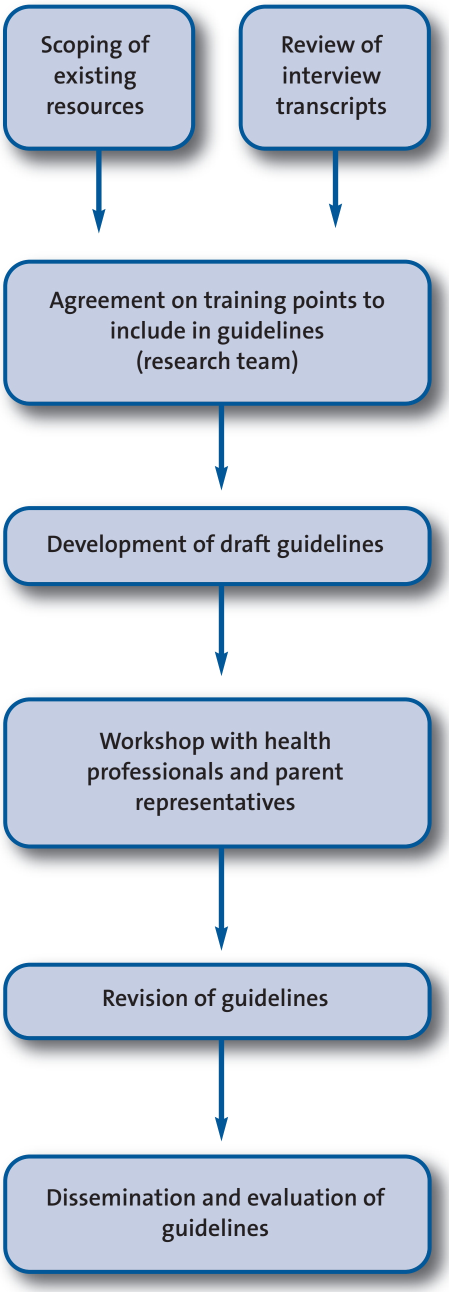

FIGURE 1 The process of guideline development.

FIGURE 2 At the workshop, the participants discussed the guidelines within small groups.

Acknowledge the bereavement

Parents usually welcome the opportunity to discuss the multiple who died and often feel that their loss is underestimated because of a tendency of others to try to be positive and focus on the surviving multiple. Staff reported that sometimes they may focus too much on the surviving multiple and regret not giving parents the opportunity to reflect on their bereavement.

Provide emotional support

The relationship staff establish with parents while they are on the ward or in regular contact (in out-patient or primary care settings, for example) can be enormously helpful to the parents. Parents generally value the empathy and support they receive from staff during this time. It is important that the value of talking to parents and providing emotional support to them is recognised.

Provide appropriate information

Ensuring parents are provided with accurate information and support, and opportunities to access information and support on an ongoing basis, was identified as being very important. Parents appreciate being 'kept in the picture' and informed of what to expect throughout the pregnancy. Staff should work in partnership with parents; this means making joint decisions. In order to facilitate this, parents need to be well informed and involved in discussing potential risks and developing care plans.

Provide continuity

Parents appreciate continuity of staff and seeing familiar faces as much as possible. Where staff changes are necessary, due to the practicalities of staffing a busy unit, and when families are transferred between wards, hospitals and departments, it is very helpful if all staff ensure that information is communicated effectively. Parents find it painful to have to retell different individuals about the death of their multiple or for staff not to realise that their baby is a surviving multiple.

Offer memory making

Parents usually value and find comfort in photographs and mementos of their deceased multiple and appreciate having a record of both of their babies together. It is a good idea to keep copies of photographs (and any other mementos) as sometimes parents do not want them at the time, but regret not having them later. Other mementos to consider making include footprints, handprints and memory boxes.

Handle cot occupancy sensitively on the neonatal unit

Often there will not be sufficient flexibility to provide all parents with ideal accommodation for themselves and their babies. It can be painful for parents who have lost a multiple to be surrounded by other multiples and to see them being visited and their 'special status' celebrated by their visitors. Wherever possible (and after consultation with the parents), it might help if a surviving multiple can be placed in a ward or bay where there are no other sets of multiples.

Prepare parents for discharge from hospital

Some parents spend a long time on the neonatal ward while their surviving multiple is cared for. The time of discharge from hospital of their surviving multiple back into the real world can be a difficult and stressful time. Good communication with, and transfer of information to, community services at the time of discharge is vitally important.

Conclusion

The iterative process of developing guidelines for health professionals involved in supporting parents who have suffered a loss from a multiple pregnancy using co-design methods is described.

The work was undertaken in response to the findings of a previous study showing that staff felt ill-equipped to support parents in these circumstances.[2] Staff that were interviewed expressed a wish for more training in this area, demonstrating the need to ensure effective dissemination of the guidelines and evaluation to ensure they are reaching their intended audience. The use of electronic media (for example, web-based discussion) will help to facilitate this.

Acknowledgement

The authors wish to acknowledge the financial support of the Academic Health Science Network (AHSN) North East and Cumbria and the Tiny Lives Trust. They thank all the health professionals and parents who took part in the workshop.

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. **Richards J., Graham R., Embleton N. et al.** Parental perspectives on the perinatal loss of a co-twin: A qualitative study. *BMC Pregnancy Childbirth* 2015; 15:143.
3. **Bryan E., Hallett F.** *Bereavement. Guidelines for Professionals.* London: Multiple Births Foundation; 1997.
4. **Robert G., Cornwell J., Locock L. et al.** Patients and staff as codesigners of healthcare services. *Br Med J* 2015;350:g7714.