Communicating effectively with parents whose child has died
Parr, Eloise; Littlemore, Jeannette; Turner, Sarah; Taylor, Julie; Topping, Annie

License:
None: All rights reserved

Document Version
Peer reviewed version

Citation for published version (Harvard):

Link to publication on Research at Birmingham portal

General rights
Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- Users may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy
While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.
Communicating effectively with parents whose child has died

When parents experience the death of a child, no matter how old their child was, they experience a range of complex emotions that are sometimes difficult to articulate. A strong understanding of the emotional impact that the bereavement will have can help funeral practitioners to provide compassionate care. Parents provide mixed accounts of the communication that they had with funeral practitioners with some reporting highly positive experiences of compassionate communication and others reporting less positive experiences. In order to find out what constitutes good communication in the eyes of parents, we conducted a study, funded by the True Colours Trust[^1], in which we investigated the experience of parental bereavement, itself as well as parents’ perceptions of good and bad communication with funeral directors.

We interviewed 24 bereaved parents and asked them, among other things, their experience of organising the funeral, the kind of funeral they had chosen for their child, what they wished they could have done or what could have happened, and their perceptions of the communication they had had with funeral directors. We also asked them about the experience of bereavement itself. Here we report some of our findings, which we believe may be of interest to funeral directors who are helping parents to organise a funeral for their child.

Our findings indicate the importance of time, empathy, and the recognition of the possible emotional and physical reactions in response to grief and bereavement. These factors affect the requirements and expectations of the parents of their experience with funerary services and professionals.

Many parents in our study described the almost ‘physical’ effects of grief and loss on their ability to engage with the world and make decisions. One parent described feeling as if her head was ‘full of cotton wool’ and that this made choosing funeral arrangements with the funeral directors extremely difficult. Others described their inability to even look at a catalogue or process the sheer amount of decisions they have to make for a funeral. The experience of the parent quoted above, as well as many others we interviewed, emphasise the impact bereavement can have on a parent’s state of mind. This means that effective communication requires a sensitivity to the states of mind of the bereaved, and a recognition that they may not be in the right frame of mind to receive all the necessary information at once. Many parents emphasised the importance of information and choices being given but expressed that they can be overwhelmed and need time to process.

Some parents were particularly thankful when funeral directors gave them time to gather themselves during the funeral planning process. When asked what advice they would give to professionals working with other bereaved parents, many said that giving them time and space is really important. As one parent said:
Timing seems to be really important, like giving you time and space … And not hitting you with a whole load of stuff at once. … And realising we might change our minds at times. … We can’t always be ‘logical’ Your mind is just messed up

Our findings also emphasised the importance of funeral directors explaining to parents what is happening at certain times and why they are doing what they are doing, especially if the process takes some time. When this is not done, parents’ experience of care is jeopardised. One parent explained how they desperately felt they needed to see their child in the funeral home shortly after his body had arrived there. The funeral director recommended that the parent wait a few days in order for them to make the body more presentable, or as he explained it ‘make him look like your [child]’. The parent reflected on the honesty of this statement as it gave her a valid explanation of why she would have to wait. Without this explanation this parent could have experienced unnecessary stress in not knowing why she could not see her son immediately.

Another important aspect highlighted by our findings was the importance of empathy and recognition of how bereavement can shape a parent’s identity. For many, the loss of a child threatens their identity as a parent, so it is important for funeral directors and other professionals to be aware of the identity of both the parent and the child. This can be demonstrated by allowing parents to enact parental responsibilities like dressing their child or reassuring parents that they will ‘look after’ the child’s body on their behalf. One parent described the relief they got from being told by the funeral director that their child was ‘safe’ as ‘even though you know by then it’s just your child’s body, you still don’t want your child to be alone’. Another parent was particularly touched by the funeral director asking if they wanted to dress their child in pyjamas and put him to bed as they did not know that was an option. However, in some cases, parents were told that they were not allowed to interact with their child following the death, which caused extreme distress, often exacerbated by insufficient explanations and management of parent expectations. In these cases, these parents wished they had been able to at least see at least a part of their child as the rest of the child had been deemed too upsetting to look at. The fact that they had not been allowed to do so made it much harder for them to accept their child’s death and process the experience. As one parent put it:

I couldn't see my son … having the options of other things - you know, even partially opening the casket, or offering me his hair, or his fingerprints would have meant that I could have perhaps accepted it more.

Parents did not appreciate being given vague reasons for why they could not see their children such as the fact that things are ‘in process’. Expressions like this could sound both vague and technical and their meaning was not always clear to them.

‘Small and unexpected acts of kindness’ were a recurring theme throughout the interviews, with one parent describing them as ‘lights in the darkness’. One of the parents who we interviewed told us : ‘I was in such a fragile hurt state, that any small act of kindness would have made a
massive difference’. These acts of kindness often took the form of simple acknowledgement of the personhood of the child. One parent strongly appreciated the fact that the funeral director had asked about the personality of her two-month-old baby:

What he was like, why we’d had him, his little things that he did. You know, which is hard when they’re only two months old, but it was still nice that somebody recognised him as a person, as his own person

Sometimes these small acts of kindness came from unexpected quarters, from people who work on the periphery of the funeral industry. One parent, for example, commented on a poignant visit that she had made to the florist to arrange flowers for the funeral:

That little flower shop, we went – one of my sisters was there and NAME and we were getting flowers for my mum as well, so we ordered a lot of flowers. And I was explaining it was for my daughter and the young girl looked fairly shocked, but she was doing it all quite efficiently, writing it down and sorting out the flowers. And I could see the manager just doing something behind, messing about with the flowers and I didn’t think much of it and as I went to go out he just came with this huge bunch of flowers and he said, ‘To brighten you up at home’ [laughs]. That was a very nice, a very, very nice thing to do

In this short article we have seen some poignant examples of what parents deemed to be effective and less effective communication with professionals working in the funeral industry and related businesses. We have seen that grief can be so overwhelming that parents sometimes struggle to take everything in at once, and that timing is therefore important when communicating about funeral details. We have also seen the importance of acknowledging the continued identity of both the parent and child. Finally, we have seen that small acts of kindness can make a significant difference to their experience. Many of the parents who we interviewed expressed a wish that bereaved parents in future would benefit from their stories being heard. By reporting their experiences in this article, we hope to have gone some way to bringing their wishes to fruition.

Authors

Eloise Parr (University of Birmingham), Sarah Turner (Coventry University), Jeannette Littlemore (University of Birmingham), Julie Taylor (University of Birmingham) and Annie Topping (University of Birmingham).

Acknowledgements

We would like to thank the True Colours Trust and all the families for their help with this project.
https://www.truecolourtrust.org.uk/