

## 'Lights in the darkness', Part 2

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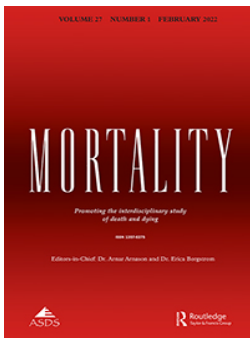
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# 'Lights in the darkness', part 2: characterising effective communication with professional groups following the death of a child

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## ABSTRACT

In this two-part article, we investigate communication with parents following the death of a child. Parents who have lost a child need to communicate with a wide range of professionals, and the quality of the communication that parents have with these groups can radically affect their experience of bereavement. In this UK-based interview study, we investigate why particular types of communication are deemed particularly (in)effective, by examining them in the light of parents' descriptions of the experience of loss. In the first part of the article, we reported findings from our in-depth content analysis of these interviews, discussing the ways in which the death of a child was experienced and how their accounts relate to previous work in the area, and then exploring the parents' accounts of the kinds of communication they had with healthcare professionals involved. In this second part of the article, we consider the wider network of professionals with whom parents may come into contact following the death of a child. We conclude by discussing the ways in which effective care and communication resonates with, and takes account of, the experiences of the bereaved.

## KEYWORDS

communication; bereavement; death of a child; interview-based study; child loss

## 1. Introduction

This is the second part of a two-part article reporting the findings from a project, funded by the True Colours Trust, which was designed to inform better care of bereaved parents by gaining insights into the experience of child death, and subsequent communication with the range of professionals encountered. In this project, we interviewed parents or carers, who had lost a child, about their loss, and the communication they recalled having had with a range of professionals.

As we saw in the first part of this article, the death of a child engenders a range of intense and complex emotions that may be difficult to articulate, and bereaved parents may struggle to communicate how they feel to those who are there to support them (Arnold & Gemma,

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2008). However, despite these difficulties, we noted that the presence of a supportive and understanding social network is of great importance in supporting the grief process (Riley et al., 2007). We also noted that it is important that the support is perceived to be effective by those receiving it (Breen & O'Connor, 2011), and that difficulties in communication may have a deleterious impact on the effectiveness of the support on offer.

Parents of children who have died need to negotiate a complex network of people and agencies that may be potential sources of support, as introduced in the first part of this article. This network may include healthcare and bereavement support practitioners, registrars, coroners, the police, funeral professionals, and religious institutions and spiritual leaders. The ways in which the various players within this network communicate with the bereaved, the language they use, what they do and do not say, and what they do and do not do, can all have a deep and lasting impact on the parents. The different stages of the process following the death also present distinct challenges. An understanding of the emotional impact that the bereavement will have will help those who support parents to provide compassionate care, as it will allow them to take account of the parents' state of mind and the ramifications that the bereavement may have.

In the first part of this article, we reported our findings as they related to healthcare practitioners and bereavement support workers. In this part of the article, we focus on parents' communication with (a) professionals involved in official procedures (registrars, the coroner's office, the police, and others), (b) funeral professionals and (c) religious institutions and spiritual leaders. We explore the experiences that bereaved parents recall about the communication with this wider network of professionals who supported them, and relate these experiences to the parents' descriptions of the psychological impact of the loss.

## 2. Materials and methods

Semi-structured interviews were conducted with individuals or couples in the UK, in which bereaved parents were asked about their experiences of child loss and the communication they had with professionals following their bereavement. The study received ethical approval from the University of Birmingham (ERN\_19–1582). Further information on the methodology employed can be found in Part 1 of this article.

## 3. Results

In Part 1 of this article, we discussed the experience of the bereavement, and discussed parents' communication with healthcare practitioners and bereavement support workers in light of this. In this part of the article, we broaden our discussion to consider what parents said about their communication with the wider network of professionals, including professionals involved in official procedures, funeral professionals and religious institutions and spiritual leaders. Throughout this section, we consider *why* particular types of communication are deemed particularly (in)effective, by examining them in the light of parents' descriptions of the experience of loss, as seen in Part 1 of the article.

### ***3.1. Professionals involved in official procedures: registrars, the coroner's office, the police, and others***

Following the death of a child in the UK, parents have to face a complex set of bureaucratic tasks and procedures. First, they have to register the death at the Register Office and may have to deal with the Coroner's Office, e.g. if the cause of death is unknown. They may also need to perform a series of more mundane tasks, which will vary depending on the age of the child; they may involve anything from cancelling child benefits and informing childcare providers to closing bank accounts and cancelling utilities. While these tasks may appear quite straightforward and mechanical on the surface, they may be challenging for the bereaved parents because of what they represent. They may also involve technical terminology that may seem opaque, especially given the state of mind of the parents.

With the exception of coroners, some professionals within these roles may have less experience with the specific needs of the bereaved than the healthcare practitioners discussed above, as in many cases their day-to-day jobs are unlikely to involve much interaction with bereaved individuals. The mechanistic and procedural nature of these activities may make it difficult for them to be performed in an empathic way, especially as there will not have been many opportunities to build rapport with the parents. A particular challenge for professionals working in these areas when dealing with bereaved parents may be the need to switch quickly between relatively upbeat activities (such as registering a marriage) or everyday activities (such as helping someone to open a bank account) to a much more delicate activity such as helping someone register the death of their child or to close their deceased child's bank account. Staff may lack specific training in how to communicate with bereaved parents and may find it difficult to switch between the different types of communication that are required for different activities. These difficulties may be compounded by the fact that these different activities are likely to be taking place in the same space. This poses a challenge for the parents as well. For example, several parents in our study reported that when they went to register the death of their child, they found it difficult to sit in the waiting room with parents who were waiting to register their child's birth, especially when some of those other parents had their new-born babies with them.

The ways in which professionals working in these areas responded to these challenges were alluded to by the parents in their accounts of the care they received. For example, some parents reported that the communication they had with staff in a coroner's office was 'mechanical', and talked about how they disliked the 'horrible form filling'. One parent (Participant 11) described the coroner as a 'horrible person', who had told her, 'it's a big deal for you but for us, it's nothing. We're used to it'. Another parent (Participant 12) commented that 'there is no sense of urgency. To [the coroner's office], it's just a file in ... a pile of paperwork', suggesting that the coroner they spoke to had become rather too caught up in the procedural nature of their tasks at the expense of recognising the distress felt by the parent. The significance for the parents of signing the forms did not appear to be universally acknowledged by all coroners.

Professionals who do not routinely deal with parents of deceased children and who are more used to dealing with routine, everyday encounters sometimes appeared to be unable to 'switch scripts'. This sometimes resulted in communication that was deemed

inappropriate by the parents. For example, one parent (Participant 15) reported that when they called their son's car insurance company to cancel his policy, the representative they spoke to kept saying that they needed to speak to the policy holder despite their insistence that this was impossible. Other parents (e.g. Participant 15) reported interactions with people in traditional customer service roles who, despite having heard their story, ended with an automatic 'have a nice day'. Another parent (Participant 19) recounted how, following the registration of the birth and death of her daughter, she was asked by the registrar, 'so what are you going to do now, are you going to go on holiday?' In these cases, what may seem like appropriate and polite language for most encounters in that setting was perceived as inappropriate by the bereaved parents who experienced it. These interactions can have an enduring impact. As one parent (Participant 15) expressed, 'that kind of thing, because you are on a hair trigger all the time, it can just push you over the edge'.

An additional challenge associated with official procedures is that many take place in a public space. Completing these procedures in public may make a difficult task even harder. Consider, for example, the case of the mother (Participant 15) who was in a queue for the counter in order to close her son's bank account, when an employee of the bank tried to persuade her to use one of the machines. When she explained that she was there to close her son's account, he asked, in front of all the other customers, 'How did he die?' The fact that this was an insensitive question to ask was compounded by the fact that it was asked in front of other people. This contrasts sharply with the experience of Participant 03, the mother who, when closing her daughter's bank account, was taken into an office at the back of the bank and offered a cup of tea. There, the manager closed down the account and explained that unfortunately some of the correspondence may arrive in her daughter's name. The mother appreciated this warning, and his approach more generally, commenting, 'He made that easy and that could've been very hard'.

Although not all bereaved parents need to interact with the police, those parents we spoke to who did need to do so had strong views on the experience. Police involvement can add an extra level of complexity to an already difficult experience. However, this can potentially be mitigated by sensitive communication on the part of the police. One parent (Participant 09) whose child had died suddenly, and who feared that she may be under investigation, commented on the sensitive nature of the letter that she received from the police, in which they wrote 'We are investigating, don't think the worst'. The wording in this letter allayed her fears. In other cases, parents appreciated instances where the police were unafraid to show humanity and recognise the fact that they have lost a child. As one parent commented:

The police officer [was] sitting there in tears and she was like, 'I'm really, really sorry, it's just I have a 17 year old son' ... and you think, 'You're only human' ... showing your humanity is not a bad thing. (Participant 09)

Parents strongly appreciated police officers taking time to explain important details. Participant 13, whose daughter died by jumping in front of a train, was worried about the impact that it would have had on the train driver and about how she would feel if she were on a train subsequently that was involved in a similar incident. She recounted how a police officer had taken the time to talk her through everything that had happened

(without being too graphic) and about the support that would be provided for the train driver following the incident. He even took her on a train to allay some of her fears about travelling by train.

When parents were critical of the police, it was often because of a perception that the police were somewhat rigid in their views with a tendency to be over-categorical:

With most of the police it was a challenge and that's because for a lot of them, with what they have to do, it is right or wrong and life is more complicated than that. (Participant 05b)

For example, one parent asked her brother to collect some possessions from her house shortly after the death of her child, but the police officers at the scene would not let him enter, nor did they explain in advance that no one would be allowed access as it had become a crime scene. She reflected that it would have been better to have been told this in advance. Indeed, when police did not spend sufficient time explaining what had happened or what would happen next, this made the experience much more difficult for the parents.

The extent to which the information provided was actually correct was also a key determinant of 'successful' communication by police officers. Some police officers appear to have felt a need to say *something* even if it was not necessarily correct. One parent reported how when the police officer was going through the medical report with her, she seemed to be making up answers to her questions:

The problem I found with her bringing the report round was that she was a police officer and this was a medical report. So I had like a million questions after reading it and she couldn't answer any of them because she's not medical. And she kept saying, 'Oh you know, it's a bit like such and such' you know, just plucking stuff out of the sky. (Participant 06)

Another source of distress for parents was the use of language by police officers that put vivid images into their minds. This was sometimes done in a very direct way. One parent found it difficult to deal with the police officer's use of the expression 'she's a mess':

It's the 'she's a mess' that sticks with me and then because of that, I think we didn't dare ask the undertaker if we could see NAME at all. (Participant 13)

At other times, upsetting images could be inadvertently evoked through indirect references to the scene. One mother commented on the reference that the police officer had made to the fact that the festival bands her daughter had been wearing when involved in a road accident had needed washing, thus making her inadvertently aware of the fact that they had been covered in blood:

We identified her through her jewellery and I remember she had her festival bands that she would never take off. So erm, and they had been washed, obviously, and they'd been cut off her. So they brought them and erm, I remember when the Liaison Officer unpacked it, she said, 'Oh, they're still wet'. They were just a bit damp and I thought, you know – now, I've got an image of her – you know, having things cut off her; of course, covered in blood. (Participant 01)

Here, the parent might have benefitted from more warning and more measured, sensitive contextualisation of the information that was being provided.

Non-empathic communication could come about when police officers inadvertently made use of 'in-group' shorthand when talking about the situation in front of parents. Participant 13 reported how, immediately after informing her of the death of her

daughter, a police officer was contacted on his radio by a colleague. He picked up his radio in front of her and replied, 'I can't talk now mate, I'm delivering the dead message, ring me back'. When she challenged him about this, he did not reply. In conversation with other police officers after the event, she was informed that this officer was not following protocol; he should have either turned off his radio or used a code word.

As with the other professionals discussed, small acts of kindness were a key aspect of successful communication. One mother talked about how the police offered to break the news to her husband on her behalf and another talked of the hug that she had been given by the police officer when visiting the scene of her daughter's suicide.

Although the parents in our study reported communication with a diverse range of professionals, they identified elements of effective communication that were common to all groups. These included an ability to adapt one's communication style, showing recognition of the child, rather than just seeing the procedures as 'casework'. Parents also highlighted the importance of receiving clear, accurate information in a timely manner, with comprehensive explanations of important details. Empathy was shown to be an important element of successful communication, both in terms of recognising the difficulties involved in navigating official procedures following a bereavement, and in terms of being aware of the language used with colleagues when in the presence of the parents, and how this might be insensitive.

### **3.2. Funeral professionals**

For many parents, the organisation of the funeral will represent a particularly important step in the period following the death of their child. Funerals provide an opportunity for parents and their communities to attempt to make sense of, and come to terms with, death and the impact it has had on them (Davies, 2017; Hoy, 2013). They provide an opportunity for a community to come together to honour the life of the deceased, to mourn their death and to comfort one another. For Hoy (2013), funerals demonstrate to the bereaved that they are not alone in their grief and that they have a community they can rely on. Some understandings of funerals may also hold that they are a 'rite of passage', demonstrating the changed state of the deceased and consequently that of those related to them (Van Gennep, 1960).

In a child's funeral, some of these aspects may be particularly salient. The death of a child may seem especially 'senseless' compared to the death of an elderly person, and the power of the funeral ritual to attempt to bring some meaning to the loss may therefore be particularly relevant. The funeral is also an opportunity for the parents to demonstrate that their child had a personality, an identity and an impact on the world, which are somewhat 'taken for granted' in the case of adult funerals. Consequently, parents are likely to want to personalise their child's funeral, to make it more appropriate to the child's identity. 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 ... 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. (Participant 17)



Unlike the bureaucratic processes associated with official registration of the death or closing bank accounts discussed in the previous section, the funeral provides an opportunity for parents to exercise a degree of freedom and control in how they choose to memorialise their child in a shared, social context. However, the decisions that parents must make when organising the funeral may bring with them a certain degree of pressure to 'get it right'. These are perceived as high stakes decisions which need to be taken carefully, and parents need to be given sufficient time and space to think about them, especially given the fact that it might be difficult for them to make these decisions when experiencing a disordered sense of time or numbness (see Miles & Crandall, 1983; Rando, 1986). For example, one parent (Participant 03) commented that choosing funeral arrangements was extremely difficult because her head was 'full of cotton wool'.

Funeral directors can play an important role in this process. In our study, 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. (Participant 02a)

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, the chance that parents will perceive their experience of care as positive is jeopardised. One parent (Participant 06) 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 appreciated 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.

Working with parents who have lost a child may pose particular challenges for funeral directors, because the majority of the funerals that they organise are likely to be for deceased adults. The fact that the death of a child occurs outside the 'natural order' of events means that there are fewer 'scripts' for funeral directors to follow in terms of funeral organisation, and parents may also make requests for the funeral that seem unconventional. In our study, some parents reported the different ways in which they personalised their child's funeral, with the help of the funeral directors. For example, one parent talked about how their child had loved the 'Cookie Monster' character from Sesame Street, so they had arranged for cookies to be given out after the service. She commented on the respect that the funeral director had shown towards the box of cookies when driving to the funeral:

When [the funeral director] took them from us at the house, he didn't just shove them on the floor of the car, he actually put them on the car seat and put a seatbelt round the box of cookies ... (Participant 5a)

While such an act was probably 'out of the norm' considering usual procedures involved in organising a funeral, it was clearly appreciated by the bereaved parents.

Although it is not part of the communication *per se*, the space in which the funeral is organised seemed to affect the parents' perceptions of the experience. The decor that is often found in funeral parlours, which is more likely to be designed with older adults in mind, may be at odds with the parents' view of their child. As one parent put it:

... it's not very child [friendly] – these funeral parlours are done in a kind of – you know, a place of rest. It's more aimed at, like, elderly people really. (Participant 02a)

Funeral professionals can help to mitigate this tension by engaging in behaviours that recognise that the child's body has a different status to that of an adult, and that therefore the parents may want their child to be treated differently to an adult. For example, this parent appreciated the care that the funeral director showed towards her child's body:

The day that he moved him from the bed into the coffin, he rang and said, 'I'm just letting you know, I've just given him a big hug and I've popped him in the coffin and I've tucked him up nicely'. (Participant 06)

Incorporating characteristics such as these may go against some of the pageantry that is traditionally associated with funerals, such as the wearing of black. However, when this pageantry is replaced with a set of behaviours that is more appropriate to a child, it can be a comfort to the parents and reinforce the identity of their child.

The care that funeral professionals show towards the child's body can help to mitigate the threat to parental identity that has been caused by the death of their child. Some of the parents in our study appreciated being given the opportunity to enact parental responsibilities like dressing their child or being reassured by funeral directors that they would 'look after' the child's body on their behalf. One parent (Participant 05) 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 discouraged from interacting with, or even seeing their child following the death, which caused extreme distress. As one parent explained:

[The funeral director] strongly advised that we don't see him because the time between his return ... was too long and therefore, I couldn't see my son. I took the funeral director's recommendation but then speaking to my counsellor, she said, 'Did they offer you his fingerprints or a lock of his hair?' And they didn't and I didn't know to ask ... Why would you think to ask? So I feel really let down. So that, I think, was a massive failing. It's like there's no consistency across funeral directors, you know, because some people do offer that but that wasn't suggested and when you're in shock and it's literally weeks after you've lost a child, you don't think about those things ... When it's a very sudden death and you're told not to see them, having the options of other things – you know, even partially opening the casket, or offering me his hair, or his fingerprints would have just made it more – I would have perhaps accepted it more. Whereas, part of me was – for months, I kept thinking, 'Well, maybe he wasn't in there. Maybe he will come back'. So I think, for me, the biggest thing is what the funeral director did, telling me that, 'You really shouldn't see him'. I think that is, for me, an ongoing trauma really – the not saying goodbye. You know, I can't ever get that back. (Participant 12)

The experience of this mother shows why funeral directors need to be aware of the fact that parents may be likely to defer to them in the decision-making process, and therefore, the advice that they give can be accepted unquestioningly by parents at the time.

In this section we have seen that organising a funeral is a very important step for parents and the (perceived) pressure to get it right can make decision-making particularly difficult, especially given the parents' state of mind. Funeral professionals can help them through this process by giving them ample time to make decisions, and by accommodating requests that may seem unusual compared to adult funeral conventions. We have also seen that it is important for funeral directors to respect the continuing bond between the parent and child, and to provide ways for the parent to enact this. When parents are prevented from doing so, this can have lasting negative effects. Finally, care needs to be taken when giving advice as the perceived power relationships between the funeral director and the parents may lead parents to follow advice unquestioningly in ways they may later regret.

### ***3.3. Religious institutions and spiritual leaders***

Unlike the groups discussed so far, parents may choose not to have interactions with religious institutions or spiritual leaders. However, we include them here as parents who did interact with them reported experiences of both effective and ineffective communication.

Understandably, bereaved parents' attitudes towards the involvement of pastors, priests, or other spiritual leaders depended in large part upon their own spiritual beliefs. However, even parents who did not share the beliefs of the clergy with whom they came into contact often had very positive interactions with them. One parent explained how she and her partner asked a priest they had known for many years to officiate their daughter's funeral despite not being particularly religious, and the evening they spent together became a source of comfort for them:

We sorted out all the things that were going to happen in the funeral ... and we were just like, 'Okay, okay', and waiting for him to go. Anyway, he didn't go ... So in the end, I just got some bread, and wine, and cheese and we just had such a lovely evening and we laughed so much ... and one of the first things he did – he does is say, 'Oh God!' So when you hear a priest with his dog collar on and everything saying, 'Oh God!' ... We were three humans in tragedy and actually, it was such a lovely evening, so he went away with a real sense of our daughter, so that he could talk about her. He didn't know NAME and he just got us talking ... probably like, 'What does she like? What was – you know, what was she up to?' and then it was just so lovely to be able to talk about her, which we did for a really long time and without us knowing, he completely took the flavour of her ... we didn't pray, we didn't do anything like that. He was just completely human with us and he wouldn't accept any payment for doing the funeral ... he was just really expert at gaining information from us and painting a picture with all the images that we were giving him and all the stories that we were giving him. (Participant 01)

She later explained how the priest made a great effort to incorporate what he had learned of their daughter into her funeral service, and that the level of 'humanity' that the priest showed in his visit was extremely helpful to her. Other parents shared this view, explaining how they very much appreciated the work of people working in religious or spiritual roles, so long as this was not seen as an attempt to proselytise:

[The vicar] just came in, he just kept saying, 'This is so awful, I'm so sorry', which is exactly, exactly what people need to say. 'Oh yes, but it could be worse', or you know, 'Time will heal', all of that, they don't need to say any of that, they just need to say, 'This is terrible, I'm so sorry', and he did exactly that. (Participant 03)

Participant 02a below also stressed the importance of people working in religious institutions prioritising a 'listening ear' over religious doctrine:

I'm anti-religion, but I'm not (anti) religious people, apart from one or two really trying to be a bit too much. He was very – you know, he was a vicar and he was religious, but he was very understanding of our situation at the time that we're not gonna be like going, you know, 'Praise the Lord' and all that kind of thing. So he was really good. He wasn't – well, I assume he wasn't trying to convert us, but he was just really good and he'd just come along and just sit and listen to us ... he didn't try and preach to us and teach to us, tell us how we should feel, he just let us talk ... I'm quite anti-church, but he was a fantastic advert for the church in terms of doing what I believe is what they should really be doing which is just being that shoulder to cry on, a listener and he was really good. (Participant 02a)

Participant 02a later went on to explain that despite holding her child's funeral in a church, the vicar made an effort to focus on the nature of loss and the more secular aspects of the bereavement during the service, rather than on more religious elements. Another couple appreciated the way their vicar brought this 'human element' into the funeral service:

Participant 05a: And [the vicar] did cry at one point, because we were right at the front and there was one point where we could tell he was upset and actually that helped because I think whether you've got a vicar or a celebrant, if they're too detached, you lose that sense of ... it's just someone reading a piece of paper at the front ...

Participant 05b: Yeah, whereas if the celebrant or the vicar actually ... steps into that process and that space with you, particularly when it's a child, I think that is massively helpful.

Members of religious institutions often have an important role to play in funerals or memorial services and conducting these services with sensitivity and respect to the child's individuality has a positive impact on the parents. As well as bringing in a personal knowledge of the child, parents noted that smooth organisation and an ability to make changes in response to the parents' wishes was also welcome. In one case, the vicar was also able to offer a creative solution to the fact that the parents (Participants 5a and 5b) did not want hymns at the service as their son did not like them. He pointed out that the hymns are there 'so that people stand and put their minds somewhere else, for a few minutes, before they get back to the intensity of the service ...' As their son loved the Cookie Monster from Sesame Street, he suggested telling the attendants that there would be a cookie at the end of the funeral, which would both '[let] people know that this funeral will come to an end, you've only got a few more minutes in this intensity and then the minute they move away, they get a cookie, which is something so random and delicious', and was personal to their son's preferences. We saw above that the funeral director continued to show compassion by 'looking after' the cookies and recognising their importance for the parents.

In contrast to these positive interactions, parents also shared examples of communication with spiritual leaders that was unhelpful or damaging to them. In some cases, these involved an over-emphasis on religion and faith at the expense of the very 'human' grief playing out:

He was so religious ... so religious and all I remember is him sitting here saying, 'Right, I'm going to say a prayer', and I remember he had his arm up in the air as if – I don't quite know what he was conjuring but anyway – and he said this really religious prayer. (Participant 01)

In some cases, this close adherence to spiritual belief led to comments that were taken as callous or even cruel by the hearers:

A lot of the Catholic priests that I did know at the hospital, they were saying things like, 'Well, it's God's will and she's in a better place'. And lots of people would say, 'God must've needed another angel' and I did say to myself once, 'The next person that says that is gonna be an angel themselves' cos I was so fed up with it, so fed up with it. Why people would say that – but people seem to need to say something. (Participant 03)

One parent explained how the hospital chaplain's failure to remember her son's name led to an incident she found amusing in retrospect, but that at the time was very distressing:

I wanted the chaplain, the hospital chaplain to go – I mean I didn't necessarily need him to come and see me, I just wanted him to go and hold NAME's hand and say a prayer to him. And even that was just too much for them to sort out at the hospital. He came and he was ridiculous ... I mean I can say this now because it's been a bit of time, it was like he was from Jeremy Beadle<sup>1</sup> [laughter]. Honestly ... he was like a hoax chaplain. A part of it wasn't his fault because he wasn't allowed to see NAME, just like we weren't allowed because this doctor hadn't been, so he wasn't allowed in to say this prayer to [NAME] ... So in the end he said, 'I can't stay any longer', the chaplain. So he said, 'Can I just say a prayer with you guys instead?' which really I didn't want. I just wanted him to go and be with NAME ... in my eyes he was making his journey to heaven, so I just wanted him to say a prayer to NAME. But anyway, that didn't happen and we both come from really big families and we were just squashed in this relative's room and he was trying to say a prayer and he couldn't remember NAME's name. He just kept saying like, 'Take our brother' because he just couldn't remember. It was horrible. And then he just kept repeating the Lord's Prayer over and over again [laughs]. And like everyone was saying Amen to try and make him stop [laughter], but he just saw it as encouragement and then carried on! In the end [my partner] just stood up and said, 'Thank you, that's enough now, thank you'. So he toddled off [laughter]. (Participant 06)

As these examples show, for those working in religious or spiritual roles, it may be helpful to be mindful of the extent to which religious belief is at the forefront of the interaction. As Participant 01 advised, 'leave ... religious beliefs behind, and come as a human who's the vicar, not come bringing God and the Bible' unless it is very clear that this is what a bereaved parent wants. While spiritual beliefs are likely to be a source of comfort for many, care should be taken to ensure that these beliefs are not used as a perfunctory panacea or 'sticking plaster' to attempt to make parents feel better about their loss.

## 4. Discussion

Taken together, the findings from our study as presented over the two parts of this article reveal a number of themes that characterise effective communication by the wide range of professionals following the death of their child. Table 1 details some of the key aspects of effective communication that we found in our study. We include those aspects that are common to all professionals, and those that are particularly relevant to certain groups.

The findings discussed in this part of the article provide further support for the conclusions drawn in Part 1; that communication encompasses both words and actions, and kindness, empathy, and the use of sensitive language and practice are important elements of successful communication. The avoidance of jargon or field-specific vocabulary was appreciated by the parents, as long as this did not come at the

**Table 1.** Characteristics of effective communication with parents whose child has died.

Professional group	Effective communication
All professionals	<ul style="list-style-type: none"> <li>● Use time effectively</li> <li>● Express empathy towards parents and their needs</li> <li>● Show empathy towards and recognition of the child</li> <li>● Clearly provide the correct information using appropriate/sensitive language, and avoid jargon (taking account of the parents' state of mind)</li> <li>● Offer small acts of kindness (where appropriate)</li> </ul>
Healthcare practitioners	<ul style="list-style-type: none"> <li>● Allow parents to feel cared for and believed, and that their child is being cared for</li> <li>● Show patience – recognise the need to give the parents time and not to rush them through the various procedures or difficult decisions</li> </ul>
Bereavement support workers	<ul style="list-style-type: none"> <li>● Be aware that the bereaved have gone through a specific experience which may be experienced very differently to other types of grief, and treat them accordingly</li> <li>● Offer empathy and support by listening to the parents about their child and only offer help or advice if wanted</li> <li>● Only offer any attempts to “fix”, or a more directive style of support if it is welcomed</li> <li>● Be guided by the individual as to the style of support that would most suit their situation</li> </ul>
Professionals involved in official procedures	<ul style="list-style-type: none"> <li>● Be prepared to adapt communication style; show empathy and recognition of the child, rather than just seeing the procedures as “casework”</li> <li>● Provide clear, accurate information in a timely manner</li> <li>● Make considerations of where the communication takes place – preferably in a private room</li> <li>● Show empathy towards the parents and the difficulties they may experience when navigating the system</li> <li>● Recognise the child as an individual rather than a “case number”</li> <li>● Be aware of language use with colleagues when in the presence of the parents</li> <li>● Take time to explain important details</li> </ul>
Funeral professionals	<ul style="list-style-type: none"> <li>● Recognise any possible resistance to making difficult decisions, and accommodate this where possible</li> <li>● Recognise that parents may not be in the right frame of mind to receive all the necessary information at once</li> <li>● Acknowledge the continued identities of both the parent and child and the bond between them, and support the enactment of these where possible</li> <li>● Take care when giving advice, in recognition that parents may defer to funeral directors in the decision-making process in ways they may later regret</li> <li>● Explain things as they are happening; provide options that are available and discuss the potential consequences of these</li> </ul>
Religious institutions and spiritual leaders	<ul style="list-style-type: none"> <li>● Recognise the extent to which parents want religious belief to be at the forefront of the interaction</li> <li>● Avoid overtly religious or spiritual language if unwanted</li> <li>● Offer empathy and support by listening to the parents about their child and only offer help or advice if wanted</li> </ul>

expense of clarity. For the parents, such vocabulary could include particularly technical and/or graphic language from healthcare practitioners, funeral directors, the police and those involved in official procedures after a death, but could also extend to unwanted religious or spiritual communication. Equally, it is important to communicate all the necessary information clearly. A failure to do so can lead to parents receiving incorrect or incomplete information during crucial moments, which may be distressing and could also lead to parents making decisions based on incorrect or inadequate information. As we saw in Part 1, the importance of parental identity and the continuing bonds between parent and child should also be recognised and supported.

Whilst all the characteristics of effective communication identified from the parents' accounts are undoubtedly important for all those interacting with parents in a professional capacity, a number of characteristics of successful communication are especially pertinent for particular professional groups. For example, an awareness of the discomfort engendered by aspects of the physical space, such as a lack of privacy and shared purpose, appeared to be particularly important for professionals in roles associated with official procedures that take place after the death of a child, including the registration of the death. A lack of privacy had a significant effect on how the quality of the communication was perceived. Similarly to the findings reported in Part 1 regarding the bereavement support workers, those in pastoral roles, such as spiritual leaders, should strike a balance between listening and advising, and avoid attempts to 'fix' them or the situation, instead following the lead of the parents.

Finally, in all areas of professional communication, it was the small gestures, or as one parent put it, the 'lights in the darkness', that made all the difference. Our interviews with parents have shown that these small acts of kindness were not limited to the professionals more commonly associated with providing emotional support, but can come from various, often unexpected, quarters. The nature of a small act of kindness may be situationally specific, changing according to the professional group and the personal needs of the parents. However, they can generally be defined as small, simple actions that recognise the parents and the child as individuals and clearly indicate care and attention; in some cases, they could be considered as being 'above and beyond' the specifics of the job role. Some parents described these acts as demonstrating 'humanness', or an element of personal involvement with the situation. Offering a warm drink to accompany difficult conversations, taking care to treat objects associated with the child (e.g. hospital bracelets, blankets, photos) with respect and presenting them to the parents thoughtfully where appropriate, or spending a little extra time with a distressed parent following the completion of 'formal' duties may all constitute small acts of kindness. These appear to be an important aspect of effective care, and for many parents they have a far greater impact on the perceived overall quality of the experience than may be expected from such simple actions. As one parent put it, 'that tiny bit of kindness has stayed with me', referring to a nurse she felt was particularly compassionate when she went to pick up her daughter's things from the hospital.

In general, effective communication entails recognition on the part of professionals of the feelings and experiences of the bereaved, and takes these into account. This involves acknowledging the bereaved as parents and accepting the unique and varied nature of their experiences. This understanding includes recognising that the bond between parent and child continues after death. Parents may need and want to continue to provide

parental care for their child as if they were still alive. When the parents cannot care for their child, the responsibility falls on the professionals who have the child in their care, which means they must reassure the parents that they are fulfilling these duties. Ultimately, however, our research has demonstrated that while there is no 'one size fits all' approach to effective communication following child death, communication that demonstrates patience, empathy, sensitivity, and attentiveness to the parents and their individual experiences is likely to be valued and appreciated.

The findings from our study also provide a springboard for further research. Whilst the small sample size allowed us to conduct in-depth qualitative analysis leading to a rich description of the experiences of the bereaved parents, it does mean that care should be taken in generalising to larger populations. It should also be noted that the sample consisted primarily of women. As we saw in the first part of this article, the experiences of bereaved fathers and the care that they receive after their child has died have been somewhat under-researched (Macdonald et al., 2010), and there is some evidence to suggest that fathers may at times experience grief in slightly different ways from mothers (Stevenson et al., 2017). Future research could therefore usefully focus on the experiences of bereaved fathers and their communication with the different professional groups that we have investigated in this study. There is also scope for research that explores the extent to which our findings may hold true across different demographic contexts. However, it is hoped that the present study has provided insights into the ways in which each of the professional groups is best placed to support bereaved parents following the death of a child.

## Note

1. Jeremy Beadle was a comedic English television and radio presenter in the 1980s and 1990s. He presented several programmes in which he played elaborate practical jokes on people.

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