

## 'Lights in the darkness', Part 1

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DOI:

[10.1080/13576275.2022.2081495](https://doi.org/10.1080/13576275.2022.2081495)

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*Document Version*

Publisher's PDF, also known as Version of record

*Citation for published version (Harvard):*

Turner, S, Littlemore, J, Parr, E, Taylor, J & Topping, A 2023, 'Lights in the darkness', Part 1: characterising effective communication with healthcare practitioners following the death of a child', *Mortality*, vol. 28, no. 4, pp. 627-644. <https://doi.org/10.1080/13576275.2022.2081495>

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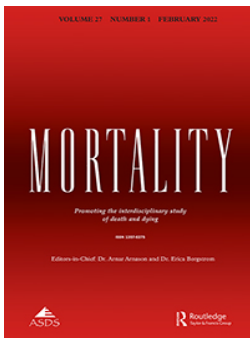
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# Mortality

Promoting the interdisciplinary study of death and dying

ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/cmrt20>

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To cite this article: Sarah Turner, Jeannette Littlemore, Eloise Parr, Julie Taylor & Annie Topping (2022): 'Lights in the darkness', part 1: characterising effective communication with healthcare practitioners following the death of a child, *Mortality*, DOI: [10.1080/13576275.2022.2081495](https://doi.org/10.1080/13576275.2022.2081495)

To link to this article: <https://doi.org/10.1080/13576275.2022.2081495>



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# 'Lights in the darkness', part 1: characterising effective communication with healthcare practitioners 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 this first part of the article, we report findings from our in-depth content analysis of these interviews, discussing the ways in which the death of a child was experienced and then exploring the parents' accounts of the communication they had with healthcare professionals involved. In the second part of the article, published in a subsequent issue of this journal, 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

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, 2008). Difficulties in communication may contribute to a feeling of isolation on the part of the bereaved. While isolation following bereavement is not specific to child death (Arnold & Gemma, 2008; Breen & O'Connor, 2011) the perceived social stigma of such a loss may put bereaved parents at particular risk (Holmberg, 2007), particularly if the death was violent (Pitman et al., 2018) or a result of suicide (Chapple et al., 2015). Such difficulties in communication are not restricted to communication between the bereaved parents and those around them. Bereaved

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couples may also encounter difficulties when communicating with each other about the loss and their grief, even to the point of relationship breakdown (Barrera et al., 2009; Lyngstad, 2013; Riches & Dawson, 1996).

The psychological effects of child death may also contribute to a sense of isolation on the part of the bereaved. Previous research has noted the all-encompassing, life-changing nature of such a loss; following the death of a child, parents are faced with a series of deep-seated, existential questions about the purpose and value of life, their 'shattered assumptions' (Janoff-Bulman, 2010) about the way the world works, and their need to come to terms with a future that no longer includes their child as expected. Part of the process of managing the grief is the need to find or create new meaning – to 'relearn, and reinvest in, a world without the deceased' (Wheeler, 2001, p. 52). The process of establishing new meanings and coming to terms with an irrevocably changed world may be particularly challenging in the case of child loss, as this form of bereavement most violates assumptions about the 'natural order' of life events, and may force bereaved parents to confront their own views surrounding mortality and their legacy as represented by their child (Miles & Crandall, 1983; Rando, 1986). For those who have not experienced such a loss, it may be very difficult to understand and empathise with bereaved parents, as to do so must also involve 'the conscious examination of rarely considered personal question about one's own life', confronting one's own beliefs surrounding mortality (Riches & Dawson, 1996, p. 5).

Despite the difficulties inherent in communication following the death of a child, the presence of a supportive and understanding social network has been shown to be of great importance in supporting the grief process (Riley et al., 2007). In her study of meaning-making following the loss of a child, for example, Wheeler (2001) identified five areas that helped parents to make meaning, of which 'connections with people' was the most cited by the participants in her study. Parents' perception of support from their social system has been related to fewer physical and psychological symptoms of grief (Christiansen et al., 2013), with strong social support constituting a key factor in shaping positive psychological outcomes for both bereavement in general (Logan et al., 2018) and parental bereavement in particular (Dyregrov, 2004). However, it is important that the support is perceived to be effective by those receiving it (Breen & O'Connor, 2011), and the difficulties in communication may have a deleterious impact on the effectiveness of the support on offer. In her study of communication following parental bereavement, Dyregrov (2004) found that an absence of norms to guide communication about parental bereavement was a strong impediment to effective communication; communication that was deemed by parents to be ineffective was characterised by: a lack of openness, a tendency to withdraw from the bereaved, a tendency to avoid talking about their child, a tendency to provide unwarranted advice, an assumption that the grief would disappear after a while, and attempts to console the parents by pointing out for example that other siblings were still alive. These observations also resonate with personal narratives of parental bereavement (e.g. Holmberg, 2007).

The network of people who are able to support a parent through the experience of child death can often be extensive, involving a wide range of professionals as well as personal contacts (Janzen et al., 2004). Communication with any one of these groups of professionals can make an important difference to the way in which a parent experiences their bereavement. In order to appreciate just how extensive and varied

this network is, it is useful to explore how the experience of a child's death, and the activities associated with such a death, roll out chronologically from a parent's perspective. Depending on the nature of the death, around the time of the death itself, parents will be communicating with, and supported by, a range of healthcare and bereavement support staff. They may encounter not only doctors, nurses and paramedics, but also receptionists, cleaners, canteen workers, and other auxiliary workers. In the immediate aftermath of the death, parents will need to communicate with professionals involved in a range of official procedures, including registration of the death and, in some cases, autopsy. Subsequently, they will need to organise a funeral, which will involve communicating with different professionals from the funeral industry itself as well as with professionals working for related industries, such as florists and caterers. During this time, support is sometimes available from, or offered by, religious institutions and other spiritual leaders. In some cases, where the child has died unexpectedly e.g. of sudden infant death syndrome, or where the child has died in suspicious or unusual circumstances, the police may also be involved.

Communication with any one of these groups of professionals can make an important difference to the way in which a parent experiences their bereavement. 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 will have.

Despite the attested importance of effective support, much of the literature on support following bereavement focuses on the care that the bereaved receive from their existing social network; there has been somewhat less research into communication with *professionals* following the death of a child. The research that has been conducted in this area has largely focused on support provided by healthcare practitioners in the hospital setting. For example, Cook et al. (2002) interviewed families whose child had died a sudden and unexpected death about the bereavement support meeting they had attended with a hospital-based bereavement services team between 8 and 12 weeks after the death. They found the sharing of information to be a critical element of the bereavement interview, and reported that parents needed reassurance that they were not to blame for the death (Cook et al., 2002). In a broader study of hospital-based bereavement services provided following the death of a child, Donovan et al. (2015) found that there was a need for more flexibility in the services provided and a need for a 'whole family' approach to the support offered. Finally, in their study of general hospital support received by bereaved parents, Decinque et al. (2006) identified a need for a) the use of a more empathic communication style by hospital staff during the palliative phase and following the child's death, b) early provision of information on how to prepare practically and emotionally for the death of their child, and c) the facilitation of contact with other bereaved parents. Davies et al.'s (2017) research similarly highlighted the need for supportive care from healthcare practitioners in interaction with parents of children with complex, chronic, life-threatening conditions. They identified a number of important characteristics of effective communication, including the need to be aware of and adapt to the changing needs of parents in a range of contexts, and to find ways of building and maintaining trust.

The majority of studies that have investigated communication with bereaved parents have focused on specific professional groups (e.g. Stevenson et al., 2017). To the best of our knowledge, only one study to date (Janzen et al., 2004) has investigated the full range of professionals with whom bereaved parents may come into contact. Janzen et al's. (2004) study focused specifically on parents who had experienced the sudden death of their child. Participants were asked to describe the experience and make recommendations to professionals who support bereaved parents. Janzen et al. (2004) identified a number of interventions for each professional group that were deemed to be helpful. Although their study did not focus specifically on *communication* with professionals, they produced a number of findings that are relevant to our study. For example, they found that the professionals can play an important role in helping parents to regain control, to say goodbye to their child in an appropriate way and to make sense of, and find meaning in, their child's death (Janzen et al., 2004).

In our study, we build on this work to explore the experiences that bereaved parents recall about their communication with the professionals who supported them following the death of their child, and relating these experiences to the parents' descriptions of the psychological impact of the loss. The project, funded by the True Colours Trust, was designed to inform better care of bereaved parents by gaining insights into the nature of the experience of bereavement, and subsequent communication with the range of professionals encountered. In it, we interviewed parents or carers who had lost a child about the nature of their loss, and the communication they recalled having had with healthcare practitioners, bereavement support workers, registrars, coroners, funeral directors, spiritual leaders, and the police. In our analysis of the transcripts of these interviews we explored what the parents said about the loss, the choices they made, and their communication with professionals.

In this two-part article, after introducing the methodology employed in the study, we present our findings, first discussing the ways in which the death of a child was experienced by the parents in our study 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 the professionals involved. While there is a wealth of literature available on the experience and impact of child loss, and on effective care and communication following bereavement, the current study seeks to draw these two strands together. In it, we aim to 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. We argue that effective care and communication is that which resonates with, and takes account of, the experiences of the bereaved.

In this first part of the article, we focus on a) healthcare practitioners (not restricted to doctors and nurses, but encompassing the full range of healthcare staff about whom the participants spoke), and b) bereavement support workers. In the second part of the article, we will be broadening our focus to consider the wider network of professional groups with whom parents may come into contact following the death of a child.

## 2. Materials and methods

Semi-structured interviews were conducted with individuals or couples, in which bereaved parents were asked about their experiences of child loss and the communication they had with professionals following their bereavement. Participants were all parents based in the

UK, aged at least 18 years, who had lost a child of any age, who could speak English at least at a conversational level, and who were able to provide informed consent. The study received ethical approval from the University of Birmingham (ERN\_19–1582). A purposive sampling procedure was employed, with participants recruited through adverts posted by the True Colours Trust and Compassionate Friends, and other similar charities as advised by the Trust (e.g. Acorns Children's Hospice, Winston's Wish etc.). Twenty-four participants were interviewed over 21 interviews (three interviews were conducted with couples according to parents' preferences). It should be noted that the majority of interviews in our study were conducted solely with the mothers, but that two of the interviews included fathers as part of a couple. The relatively small number of male participants is likely to be a result of our recruitment procedure, as we recruited through support organisations; men are less likely than women to seek social support following bereavement (see Stroebe, 1998; Stroebe et al., 1999), and men are under-represented in research into the experience of palliative care (Macdonald et al., 2010, although see Davies et al., 2004 for a discussion of men's experiences of paediatric hospice care).

We did not collect further demographic information on the parents and their circumstances, such as their sexuality, ethnicity, education, or socioeconomic status. This is because, given the sensitive nature of the topic, we wanted parents to simply tell their story without being made to feel that they were being pigeonholed, based on for example their level of education. Our priority was to maintain a warm, compassionate tone and to keep the focus on their child. Furthermore, we were very aware of the power dynamics inherent in interview-based studies and the subsequent need to reduce the perceived distance between the interviewer and the interviewee (see Tang, 2002) and therefore did not wish to emphasise possible sources of difference, such as ethnicity, education, or socioeconomic status. We also wanted the interviews to be participant-led, and for the interviewees to feel free to tell us only what they felt was relevant to say. However, we did collect data about the ages of the children when they died and the circumstances of their deaths, and this is shown in [Table 1](#).

Prior to interview, participants were told that their interview data would be used to develop the communication skills of professionals, which would ultimately help other parents or carers who have lost a child. All participants provided informed consent. Interviews were shared between all five authors, with some interviewers working together to co-interview. In order to minimise distress for the interviewees, the interviews were held in their own homes where preferred. There was no minimum or maximum time for the interviews, and it was made clear that the interview could be paused at any time by the interviewee.

In collaboration with the True Colours Trust, a topic guide was developed that would allow us to (a) explore the participants' experiences of bereavement and (b) identify the characteristics of communication that they deemed to be effective or less effective. This served as a framework for the semi-structured interviews (see [Figure 1](#)). Open questions were used to encourage extended answers, and to allow the interviewer to elicit further detail on points of interest.

Interviews were conducted face to face ( $n = 8$ ), or via video-conference platforms such as Skype or Zoom ( $n = 13$ ), according to participant preference, location, or COVID-19 restrictions. Six of the face-to-face interviews were conducted in participants' homes and two interviews were conducted at the True Colours Trust headquarters in London. Each

**Table 1.** Information about the deaths of the children whose parents we interviewed.

Participant number	Age of child (years)	Cause of death	When death occurred
1	0-5	RTC	<5 yrs
2a, 2b	0-5	Illness (sudden)	>5 yrs
3	16-20	Illness (sudden)	>5 yrs
4	0-5	Illness (sudden)	>5 yrs
5a, 5b	16-20	Drug-related death	<5 yrs
6	0-5	Illness (sudden)	<5 yrs
7*	0-5	Illness (genetic condition)	>5 yrs + <5 yrs
8	0-5	Illness (sudden)	>5 yrs
9	16-20	Suicide	>5 yrs
10	21-30	Suicide	>5 yrs
11	16-20	Drug-related death	<5 yrs
12	21-30	Unknown (ongoing inquiry)	<5 yrs
13	21-30	Suicide	<5 yrs
14	21-30	Illness (cancer)	<5 yrs
15	16-20	RTC	>5 yrs
16	21-30	Murder	<5 yrs
17	0-5	Illness (sudden)	<5 yrs
18	0-5	Illness (sudden)	>5 yrs
19	0-5	Illness (genetic condition)	>5 yrs
20	0-5	Illness (sudden)	<5 yrs
21	2 yrs	Illness (sudden)	>5 yrs

\*interviewee discusses two child deaths associated with the same inherited condition.

Sample of interview prompts
<ul style="list-style-type: none"> <li>• Can you tell us about [name of child]?</li> <li>• Please could you describe what happened ....?</li> <li>• Please could you tell me about what happened next...?</li> <li>• How did you feel about...?</li> <li>• Can you tell me about the communication you had with the healthcare practitioners, funeral directors and registrars?</li> <li>• Can you recall any examples of particularly sensitive and effective communication you received?</li> <li>• Can you recall any examples of particularly insensitive communication you received?</li> <li>• Imagine you are talking to someone who supports people who have had an experience like yours. What advice would you give them?</li> <li>• What would you like to see changed?</li> </ul>

**Figure 1.** Sample of interview prompts.



interview was sufficiently long to allow all the topics in the topic guide to be covered, and for the participants to feel that they had nothing further to add. They lasted an average of 81 minutes (ranging from 34 to 129 minutes). Audio recordings were made with consent. In the case of Skype/Zoom interviews, recordings included video data, but this was destroyed immediately and only the audio recording was retained.

The audio recordings were transcribed verbatim and anonymised. However, with the participants' consent and often at their request, some identifying information was retained (e.g. anecdotes that would allow the participants to be identifiable to someone who knew them) because this allowed the rich, personal nature of the experience to be fully conveyed. Transcripts were sent to the participants to allow them to make any corrections or additions they felt necessary. The transcripts were coded using NVivo (released in 2020), using an inductive thematic analysis (Braun & Clarke, 2012) to identify the dominant themes that emerged when parents talked about their experiences following bereavement. We also identified the ways in which the participants talked about their communication with the different groups with whom they came into contact. We identified the characteristics of good and bad communication within each of these groups as identified by the parents, highlighting common characteristics as well as characteristics that distinguished the groups from one another. We conducted an in-depth qualitative analysis of the relationships between the themes in order to identify ways in which parents' experiences following bereavement related to their perceptions of good and bad communication. A full list of coding categories is provided in the [Appendix 1](#).

### 3. Results

In this section we present our findings, first discussing the ways in which the death of a child was experienced, and then exploring the parents' accounts of the kinds of communication they had with healthcare practitioners and bereavement support workers.

#### ***3.1. What does it feel like to lose a child and how does this shape expectations in terms of communication with professionals?***

In this section, we provide a brief overview of the main themes we identified in how parents described the experience of the death of a child. It should be noted that this is not an exhaustive account, and here we focus on those elements we consider particularly salient in explaining what constitutes effective and ineffective communication. Overall, we encountered a range of reactions that were reported by parents following the death of their child, which resonate with the existing literature, for example: isolation (Breen & O'Connor, 2011), a desire to 'join' their child (Middleton et al., 1998; Young et al., 2012) although this did not extend to suicidal tendencies, and a sense that the death was 'out of order' accompanied by a strong feeling that they should have died before their child (Miles & Crandall, 1983; Rando, 1986). We categorised the reactions reported by participants into two overarching themes that we discuss in [Sections 3.1.1](#). and [3.1.2](#) respectively.

### ***3.1.1. An all-encompassing embodied experience involving psychological and temporal fragmentation***

The descriptions of the experience provided by the parents in our study indicated that it was all-encompassing and highly embodied, with the potential to alter their views of time and space. The idea of ‘fragmentation’ occurred frequently in the interviews, either through a sense of permanently and irrevocably losing a part of oneself, or through a sense of feeling ‘out of sync’ and no longer able to participate in the world around them. As one parent (Participant 04) reported, ‘we felt like we were thrown from this one universe of wonderful normality ... just forcibly thrown out into this awful universe of just misery and pointlessness’. For her, this experience made her want to disengage with the world, and she went on to explain how she stopped wearing contact lenses and switched to glasses so she would be able to take them off easily, because she ‘just wanted everything to go away’.

Some parents attempted to take advantage of the fragmentation process, using it to compartmentalise their grief. This often met with limited success, as this parent’s account of a conversation with the attending medical consultant illustrates:

I said I’ve got my grief, I’ve put it in a box and I park it on the shelf up there. And [the consultant] looked at me and he said, yes, he said, every now and again it falls down on top of your head and I thought that was just perfect, and you can’t always tell when it’s going to be.  
(Participant 08)

Losing a child also had an impact on parents’ experiences of time. Parents reported feeling like time was speeding up or slowing down, and feeling that they had no control over events. In keeping with Rando’s (1986) observations of a lost ‘legacy’ following the death of a child, future time became more salient to many participants, who referred to the loss of a planned-for future and the loss of future relationships that would have come to them through the child such as sons/daughters-in law and grandchildren.

### ***3.1.2. Parental identities and continuing bonds***

Contemporary understandings of grief place importance on the strong relationship that bereaved individuals may maintain with the deceased. The Continuing Bonds theory of grief (Klass et al., 2014) proposes that while this relationship evolves, it remains an important part of the identity of the bereaved, and may provide a sense of continuity through the turbulence of grief (Valentine, 2018). In keeping with previous research into the role played by continuing bonds in parental bereavement (e.g. Harper et al., 2011; Toller, 2008), many of the parents in our study reported a strong and sustained bond with their child, which led to a continuing need to ‘parent’ their child. One parent (Participant 19) explained, ‘I just wanted to show her the house, even though we weren’t showing her the house because she’d died, but yeah, that felt important to me’, and other parents appreciated actions taken by healthcare professionals that demonstrated respect and care of their child’s body after their death.

Parents also commented on the challenges involved in negotiating their new identities as parents of deceased children, with one participant (Participant 01) describing how she ‘wasn’t spoken to like [her daughter’s] mother’ following her child’s death, and others explaining their difficulties in talking about the number of children they had

when asked. Some said that they occasionally omitted to mention their deceased child in conversations with others in order to prevent their interlocutor from feeling uncomfortable. This often led to feelings of guilt caused by the feeling that they had hidden or denied their child's existence and their continued identity as a parent. Many of the parents, therefore, commented on the importance of having 'safe' opportunities to talk about their children. One parent (Participant 04) explained how she found parent support groups helpful, as they gave her the opportunity to be seen as her son's mother. She explained, 'I love it. And partly I love it because I am NAME's mum when I do it and I'm not NAME's mum in any other [context]'.

We would argue that effective, empathic communication by professionals needs to take account of these experiences. In the following section we discuss our findings concerning parents' evaluations of the communication they had with people from a range of professional groups, and explore why particular types of communication were deemed particularly (in)effective, by examining them in the light of parents' descriptions of the experience of loss. We explore the ways in which effective care and communication resonates with, and takes account of, bereaved parents' experiences.

### ***3.2. Parents' assessments of effective and less effective communication with healthcare practitioners and bereavement support workers***

Having discussed the experience of bereavement and the implications that this has for effective communication, we now turn to what they said about their communication with healthcare practitioners and bereavement support workers. 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.

#### ***3.2.1. Healthcare practitioners***

When a child dies, the first professionals with whom the parents come into contact are often healthcare practitioners. The relationship between bereaved parents and healthcare practitioners is key in the period surrounding the death of a child (Brosig et al., 2007). It is during this time that the parents are likely to be feeling particularly disorientated, and experiencing a strong sense of psychological and temporal fragmentation.

The fact that parents in our study were feeling disorientated and confused accounts for the fact that they appreciated being told exactly what was happening in a clear yet sensitive way. When this did not occur, it left a lasting impact on the parents. We can see an example of this in this mother's account of how a doctor told her that her child would not survive, with or without an operation, and then left without clarifying what was going on:

He came along to tell us what was going on. And I can actually remember his words, exactly word for word all these years later and what he said is, 'NAME won't survive without a liver transplant, NAME won't survive an operation, so NAME probably won't survive' and he cleared off. He didn't say to us, 'What do you understand? What do you think is going on?', any of that. And he just went. (Participant 03)

In contrast, parents appreciated clear explanations of the situation and what was happening to their child. Here a parent recounts how the nursing staff would explain everything they were doing to their child's body as they went along:

They would tell us what they were doing [...] 'We're just gonna do this, gonna clean NAME's mouth so she feels nice and comfortable' and they would tell us what they were doing. And 'We're just gonna give her a little wash and freshen up' or whatever. (Participant 03)

The example above also demonstrates an understanding by the nursing staff of the continuing bonds experienced by the parents. This was appreciated by many of the parents we spoke to, who deemed care to be more effective when they felt that their child was being cared for even after death.

In addition to feeling that their child was being cared for, parents also appreciated feeling that they too were recipients of care. For example, one parent remembered how the nurses had made sure they went home for rest and reassured them that their child would be safe in the hospital. Conversely, another mother commented on the lack of care and attention paid to her, including not being offered drinks as she waited in the hospital. Another key factor of effective communication with healthcare practitioners in the eyes of the parents was the extent to which parents felt that they had been listened to and believed. One parent reported how she was told repeatedly that it was impossible for her child to have died from a particular condition, despite the fact that her child had suffered from this condition in the past and she was able to recognise the symptoms. In this case, it turned out that her child had in fact died from this condition.

The need for clear yet sensitive communication also included the need for sufficient information to be given. At times parents were given leaflets for bereavement services, but some recalled being handed these without any explanation of their usefulness in the future. One parent recounted being handed some leaflets in a plastic bag and simply told, 'here are some leaflets'. Other parents reported similar experiences of being given items without explanation, for example being given memory boxes by healthcare practitioners. They were not told what was in the box or what it was for, and as a consequence, were worried about opening it for fear of what they might find inside.

We reported in [Section 3.1.1](#) that losing a child impacted on parents' experiences of time, with parents feeling like time was speeding up or slowing down, or experiencing a lack of control. It is therefore unsurprising that the use of time was a recurring theme when our participants talked about their communication with healthcare practitioners. One parent (Participant 04) commented, 'the best thing about being there was that [...] they gave us time and space. They didn't rush us'. In contrast, one mother reported her distress when the doctor immediately started talking about the post mortem as soon as she had learned of the death of her child. She felt that this was too soon, as she had not had time to process the fact that her child had died.

To sum up, effective communication with healthcare practitioners took account of the parents' state of mind immediately following the bereavement and was characterised by sensitivity, a willingness to believe the parents and to respect their views and experiences, and a willingness to care for the children even after they had died. Effective communicators also recognised the need to give the parents time and not to rush them through the various procedures.

### 3.2.2. Bereavement support workers

Some participants sought or were offered counselling or other psychological support following the loss of their child, and they reported a range of experiences of such care. When participants were critical of the bereavement care they received, in some cases these criticisms were related to the fact that the care was insufficiently tailored to their own experiences. Some parents felt that their counsellors equated grief to diagnosable mental health conditions such as depression and anxiety. This was felt to be inappropriate by the parents, who felt that their reactions were justifiable responses to their bereavement and should not be likened to a mental health condition. Some parents reported that professionals used depression/anxiety severity scales which they did not consider appropriate to the situation at hand, and led to conversations such as the following between a bereaved parent and a counsellor:

One of the sessions [the counsellor] went, 'You know, we're concerned about you cos you're raising very high on the suicidal thing' and I was like, 'I'm not suicidal, okay? The last thing I wanna do is leave my wife and . . . new baby'. So I just said, 'Look, you haven't listened to a word I've said. All you've taken down is these stupid scores on your piece of paper and you've not put any context into what I've said'. (Participant 02a)

This parent reported a similar experience with her doctor:

When the doctor rang me to triage what our needs were, she'd not read the notes section where I'd said NAME had died. She'd just gone down the depression and anxiety questionnaire and she was reading the questions out . . . 'Do you want to die?' I think one of the questions is, and I burst out crying and she was like – and obviously then read the notes – and she was like, 'Oh my God, oh my God' and I said, 'I don't want to die, but I miss NAME and I want to be where he is'. That's different to me, I'm not saying I'm gonna go and kill myself, I'm just saying I want to be with NAME. And so the questionnaire is not appropriate'. (Participant 06)

If the use of these scales is necessary, a clearer explanation of their role may help to make parents feel more comfortable.

A lack of personalised, nuanced care was sometimes felt to be the result of a lack of shared experience. Some counsellors gave the parents the impression that they were prioritising their academic knowledge over the parents' lived experiences, appearing arrogant or overly didactic in the process:

[The counsellor] was textbook and it's so frustrating dealing with people who have not gone through what you have gone through. They've learnt lots of stuff from books and think they know how you should feel. [. . .] You felt like he was almost lecturing to you and it was utterly pointless . . . We've had more benefit by talking to other parents who've lost children. (Participant 02a)

Those participants who considered their formal bereavement support a positive experience identified a number of qualities which contributed to its success. A general sense of compassion was noted as important by several participants, as it led care-givers to 'go that little extra mile, and any extra mile when you're going through something that happened to us is like a hundred miles' (Participant 02a). It was also considered important for professionals to strike a balance between nuanced, personal care as noted above, and to know when to be directive when needed.

We were allocated a bereavement worker from the hospital. I remember he was very kind, I remember he was very directive, which is kind of what we needed . . . he took us the next day to the registry office, and we registered her birth and her death, then he brought us back to the hospital, gave us a memory box . . . he kind of made the appointments, took us in a taxi, everything, erm, took kind of charge I think in terms of getting mementoes because we'd never have thought of those things, and then we'd have probably really regretted not having them, so I think we did need that bit of direction in those few days. (Participant 19)

In the eyes of the parents in this study, effective professional bereavement support requires practitioners to have an awareness of the specific experiences of the bereaved. It will not necessarily be appropriate to apply more general understandings of mental health to this experience, even if symptoms may appear similar. The parents valued having an opportunity to talk freely about their deceased child, rather than any attempts to 'fix' their situation, although there were times when a more directive style of support was welcomed. Bereavement support teams should therefore be guided by the individual as to the style of support that would most suit their situation.

#### 4. Discussion

Although our findings are based on a small sample size, the nature of the interviews allowed the participants to go into great depth about their experiences. A number of themes emerged that characterise effective communication by healthcare practitioners and bereavement support workers following the death of a child. Table 2 details some of the key aspects of effective communication that we found in our study.

While care must be taken in generalising to other populations, our findings show that communication encompasses both words and actions, and that the most important characteristics of effective communication, regardless of the professional group, are kindness, empathy, and the use of sensitive language and practice. The importance of parental identity and the continuing bonds between parent and child should also be recognised and supported; bereaved parents often desire to continue 'parenting' their children, and if they are denied opportunities to do so, this is likely to be distressing. Similarly, professionals who spend time with the child's body can have a reassuring effect on parents if they demonstrate care and respect for the body, even after death.

**Table 2.** 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</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>

For professionals in psychological or wellbeing support roles, such as bereavement support workers, it is important to strike an effective balance between simply listening to the parents and offering help or advice. Parents valued having opportunities to talk about their child and the effects of the bereavement and often wished simply for the time and space to do so, rather than being subject to attempts to 'fix' them or their situation. The experiences of the parents we interviewed highlighted a need to follow the lead of the parents, especially when offering emotional support.

In the second part of this article, we will extend our discussion to consider communication with a wider set of professionals outside the healthcare sector with whom parents may come into contact following the death of a child. This will allow us to evaluate what constitutes effective communication with parents following the death of a child within and across the different professional groups.

## Acknowledgements

We would like to thank the True Colours Trust, who funded this research. We would also like to thank all the parents who participated in our study, and we hope our research honours their children's memories.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Funding

The work was supported by the True Colours Trust.

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## Appendices

### Appendix 1. Full list of coding categories

#### 01 Bad Communication

- Dehumanization of child
- Lack of empathy
- Use of jargon
- Ineffective use of time
- Wrong information provided
- Bad advice
- Failure to communicate key information

#### 02 Good Communication

- Recognition of child
- Empathy
- Clear language
- Effective use of time
- Correct information provided
- Good advice
- Successful communication of key information

#### 03 Emotional Reactions

- Emotional reactions - negative
- Emotional reactions - neither positive or negative
- Emotional reactions - positive
- Unexpectedly powerful reactions - negative
- Unexpectedly powerful reactions - positive
- Wished for emotional reaction

#### 04 Practical Reactions and Arrangements

- Practical reactions and arrangements - negative
- Practical reactions and arrangements - neither positive or negative
- Practical reactions and arrangements - positive
- Symbolic behaviours
- Unexpectedly powerful reactions - negative
- Unexpectedly powerful reactions - positive
- Wished for practical reaction

#### 05 People Involved

- Coroner's Office and post mortem
- Counsellors and bereavement support
- Crematorium staff
- Educational institutes
- Embassies, consulates
- Family
- Grandparents
- Other
- Parents of child
- Siblings
- Florists

Friends and acquaintances  
Friends of child  
Friends of parents  
Neighbours  
Other parents and carers  
Funeral directors  
General practitioners (doctors)  
Hospital staff  
Doctors  
Nurses  
Others - hospital  
Receptionists  
Mortuary staff  
Paramedics  
Police  
Procurator fiscal  
Registrars  
Spiritual leaders  
Work colleagues, managers, occupational health

06 Funeral

07 Ashes

08 Continuing bonds

09 Loss of future

10 Defining bereavement

11 Conceptions of time

12 Metaphors

13 Ways of remembering children

14 Advice that parents would give