

PERSONAL PRACTICE

Bereavement support following sudden and unexpected death: guidelines for care

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Dealing with families who have suffered a sudden and unexpected death is a skill that may be needed by any paediatrician. Offering a bereavement follow up meeting to such families is part of accepted practice and is perceived to be of value in helping the family to come to terms with the loss. Unfortunately, there is very little guidance on the objectives for such a meeting, or the training required to help staff conduct such meetings. The nature of the work on a paediatric intensive care unit (PICU) means that staff have a greater experience of handling families in such a situation. We have reviewed our experience over the past five years following up the families of 51 children who have died suddenly and unexpectedly in our regional PICU. In doing this we have identified five key elements that we suggest are essential to a successful follow up meeting, and have supported this with case studies as illustration.

tailored to the situation. As deaths in intensive care are more common, these staff have greater experience of such meetings, and what can be achieved.

METHODS

Our regional paediatric intensive care unit (PICU) has employed a trained counsellor since 1990, who has conducted bereavement follow up in conjunction with a paediatric consultant (appointed in 1992). From 1995 to the end of 1999 in our teaching hospital there were 113 deaths on the PICU. Eighty nine involved cases of sudden or unexpected death, and families were offered follow up. Eight declined to revisit the hospital, two more postponed follow up, and 28 did not reply to the letter. Four families were not offered follow up (two of whom were suspected cases of non-accidental injury), and 20 cases involved children who had been under the long term care of other teams (especially oncology or neonatology) and were followed up by those teams. Fifty one families have therefore been seen by two of the authors either jointly or individually (PC and RRR).

Bereavement support needs to start at the time of death or even before. We maintain preprepared packs to give to all bereaved families, containing a leaflet explaining the processes that follow death (including postmortem examinations, referral to the coroner, registering the death, etc) as well as a selection of leaflets from bereavement support groups. Families are informed that we will write to them in a few months time to offer a follow up meeting, and are encouraged to seek support from any appropriate source, formal or informal.

In this paper we have focused on this follow up meeting. While it only represents a small element of the whole package of support needed after a child's death, it is an important issue and one that is not well formalised in terms of structure or objectives. The meeting involves the parent(s), and occasionally a friend. The doctor and counsellor are present. If appropriate, a junior doctor may also sit in as an observer (with permission from the parents). We believe that the medical and counselling aspects of the meeting are separate, but that both elements are very important. We have identified five key points which we believe underpin the success of the meeting (see box). Each of these sections is discussed below, with

The role of health professionals following the death of a child in hospital is not easy to define. There seems to be little published literature to support the medical and nursing staff, leading to the frequent question of "are we doing it right?". The answer to this will depend on a number of factors. The circumstances of a child's death are clearly significant and may include sudden death from injury or severe illness, or a deterioration of an existing life limiting or life threatening condition. The family's understanding of the facts, their ways of coping with the loss of their child, and the support available within and outside the family are also important considerations.

Supporting families following sudden and unexpected death is particularly difficult. Unlike children who die after a prolonged illness, there is often no time to prepare families and staff for the event, and any follow up is likely to involve staff who do not know the family well. Sudden and unexpected deaths will also occur in any hospital, affecting any paediatrician with an involvement in acute work. All paediatricians are therefore likely to need skills in handling families in (and after) this situation. Guidance on how to conduct any follow up is difficult to find and extremely subjective. There is of course no formula that can be applied. The most appropriate response will vary from person to person, and will often vary over time as well. Any follow up will need to be

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Abbreviations: A&E, accident and emergency; GP, general practitioner; PICU, paediatric intensive care unit

Key elements of a bereavement meeting

- Bereavement meetings should be delayed for 8–12 weeks following the death of a child
- All new information should be discussed with the family, and an opportunity given to review any of their clinical questions/concerns
- Issues related to childhood death, such as support for siblings or professional help needed by families, should be specifically discussed
- Revisiting the ward where a child died can be of particular importance, especially if some family members were unable to visit during the child's illness
- Staff undertaking bereavement meetings need to recognise signs of "pathological" grief

case studies from our own experience to support or illustrate our approach.

TIMING OF THE INTERVIEW

Bereavement meetings should be delayed for 8–12 weeks following the death

There are several reasons why it may be appropriate to delay a meeting with bereaved families. Most obviously, information that may have been unavailable at the time of death should be accessible prior to a meeting. Postmortem results, or other blood results taken before death, should be tracked down before the meeting occurs. The delay also allows families time to reflect on the events surrounding the death, and to generate questions that they need clarifying. Delaying for too long, however, can cause its own problems.¹ Families can feel uninformed and excluded and this can generate anger towards the hospital.

Our policy is to book the follow up to occur around three months after the death. This gives an opportunity for all results to be available (including brain histology in most cases), and for families to have formulated their questions. Not all families fit into this framework, and some families phone to postpone the appointment, an option we specifically offer in the letter that is sent out to them. Rarely, there can be a considerable delay before families become aware that they would like a meeting to discuss issues.

Case 1

One mother contacted the team through the hospital switchboard to ask for help. Her 3 year old son had died 14 years previously and she felt she needed help. Her general practitioner (GP) had suggested that she contact us. She had thrown herself back into an extremely busy schedule after the death, and as the family had grown up and moved on she felt increasingly upset by the son's death. However she felt that it was late for her to be upset by this and wanted advice.

This mother seemed to have put her grief "on hold". We were able to locate the hospital notes and reviewed the case with her. Her grief had in part been precipitated by the siblings wanting to know more about their brother and by her not remembering adequate detail. She was also anxious that she was becoming psychiatrically unwell. There were several important points about the visit. Firstly, the GP had recognised the need for help, and we were able to provide that. Equally her concerns had been taken seriously and we were able to provide important information to her about the illness. Lastly, we could reassure her that her reaction was not inappropriate in the circumstances.

In this example, professional involvement with families triggered referral back to us for a meeting that helped resolve outstanding problems.

SHARING INFORMATION

All new information should be discussed with the family, and an opportunity given to review any of their clinical questions/concerns

The sharing of questions and of information is a critical element of the bereavement interview. We believe that there are two separate processes. Firstly, we actively pass on information that has become available since the child's death. This may include new or forgotten information or a more detailed review of our thought processes during the illness, and the results of tests that came from those processes. Secondly, we offer an opportunity for families to express concerns and questions that they have about their child's final illness. This may involve anger about elements of the care given, but is often a desire to review the illness and to hear again our explanation of what was occurring. Frequently reassurance is wanted that the family themselves are not to blame for the death (for example, by not taking their child to hospital earlier).

In most cases, a discussion about the illness is enough to reassure families. We try to reduce the guilt felt by many parents by emphasising that the outcome did not depend on their actions, but honesty is essential, and this can sometimes be difficult. Although anger is common it is rarely directed towards the care on our unit, but usually towards care received in primary care or at a receiving hospital. It is likely that this emphasis only reflects the fact that we are present, but it can make resolution of the anger more difficult. In most cases, the care given to the child has been very good, and an explanation of clinical decisions may well resolve concerns. In some situations the issues cannot be resolved by all or some of the family. We then try to establish how to proceed, as in some situations it is essential that this anger (and the questions that underpin the anger) is resolved before grief can be progressed. Similarly, particular circumstances associated with the death may be important. Children who have donated organs, or those in whom care was electively withdrawn may raise very specific anxieties in the family after their death.

Case 2

A 7 year old child was admitted from home. He had had multiple neurosurgical interventions previously and had an intracranial shunt in place. He developed signs of a blocked shunt and rather than move him to his local hospital, his mother insisted on a direct transfer to our PICU. On arrival he was asystolic and never recovered. Previously, on an earlier hospital admission, also with signs of a blocked shunt, neurosurgery had been delayed, leading to a cardiac arrest with subsequent hypoxic brain injury.

This mother remained extremely angry about her son's care and her perception of negligence on the earlier admission. She was completely unable to grieve and was intent on pursuing a complaint against a middle grade neurosurgeon to the point of him "never practising again".

We felt that this mother's expectations of the outcome (for the doctor involved) were clearly inappropriate. She perceived that response to her concerns, both from the hospital and the doctors concerned, had been slow and insufficient. The surgeons involved took the view that her complaints were unjustified. Resolving the issues was important, as this mother was unable to progress with her grieving. We therefore facilitated discussion between the mother, neurosurgeons, and hospital in order to help resolve the situation. Part of this involved clarifying with the mother what processes are available for complaints about medical staff, and what outcomes can be expected from such complaints.

WIDER ISSUES

Issues related to childhood death, such as support for siblings or professional help needed by families, should be specifically discussed

We are aware that childhood death is increasingly uncommon, and that many GPs and even some bereavement groups have

little experience of childhood death. We therefore try to explore some of the rarer problems that are seen following childhood death, that may not be seen in other situations. One example is the support available for the siblings of a child who dies. Bereaved siblings are in the very difficult position of grieving but also wishing to protect their parents from their grief. They may lack the maturity of their parents in knowing how to express this, or of having support systems in their friends, who can help them to cope. We discuss the reaction of siblings and offer advice or the names of specific support groups where we feel it may be of benefit. We also run specific days each year for bereaved siblings to come together and to discuss issues that may be worrying them.

We also can become involved with parents who need a specific "sponsor". Thus for example, a family involved in an accident that has mandated an inquest may occasionally find long delays developing before they are allowed to bury their child. This can be extremely distressing, and we can offer to contact the coroner or the police to try to expedite the process.

Case 3

A young girl was admitted following a road traffic accident witnessed by her 4 year old brother. She subsequently died. The family were regular church attenders and coped with the tragedy in a fatalistic manner. The boy remembered his sister's coffin and did not then want to go back to church, which was difficult for this family. His bedtime stories had often been religious and now he was angry with Jesus for taking his sister, and worried that he might also be taken away in the night.

Advice was difficult. It was felt that the continued pressure from the family concerning Christianity, and particularly Jesus, was exacerbating the situation. The mother was advised to avoid reading stories at his bedtime that involved Jesus, and to try reading more "conventional" bedtime books.

VISITING THE SCENE

Revisiting the ward where a child died can be of particular importance, especially if some family members were unable to visit during the child's illness

The siting of bereavement meetings is of great importance. For many families, coming back to the hospital (especially if it is not their local hospital) can be very traumatic. We always arrange to meet the family at a distance from the PICU, and conduct the meeting in a room some distance from the wards. Equally, for many families it is important to visit the PICU and see the bed where their child was ill. For some parents this can somehow close a chapter and allow them to move on—they still dream that their child is in the bed. For others who may not have been able to be at the hospital originally, the visit to the wards can be an essential part of their memory of their child's last illness.

Case 4

A 15 year old boy was admitted from our own accident and emergency unit (A&E) with fulminant meningococcal septicaemia. He died a few hours later on the PICU. His parents were abroad at the time of his death and although they subsequently visited his body in hospital and were in regular telephone contact with us, they did not meet staff from the PICU until a bereavement meeting 10 weeks later.

After discussing the events of his death, we felt that his parents needed to revisit the episode,² and so walked them through the route he had taken from A&E, specifically stopping where he had stopped and explaining what had happened. Other staff who had spoken to the boy prior to his intubation were also available to reconstruct the story. Revisiting the scenes of fatal accidents is known to be helpful to grieving families to confirm or "prove" that the accident did indeed occur. In this case, the parents' absence at the initial

admission meant that they had no mental images of his last hours, which was clearly important to them.

SCREENING FOR PATHOLOGICAL RESPONSE

Staff undertaking bereavement meetings need to recognise signs of "pathological" grief

Finally, throughout the duration of the bereavement meeting, we feel it important to reflect on the response of the family members to the death. In rare situations, their response may seem particularly inappropriate. The recognition of pathological grief is difficult. The use of scoring systems (measuring health and social adjustment)³ is not practical. In broad terms we look for unusually absent or excessive reactions.⁴ Such reactions have been shown to be more likely in bereaved families following unexpected death,¹ and strategies for managing such families are well described.⁴ In this situation, discussion with that person's GP (by letter or telephone) may alert them to a problem that might require further professional help.

DISCUSSION

The agony of death can rarely have been expressed more poignantly than in a letter published in the *Lancet* in 1965.⁵ In the letter a mother describes her frustration at being excluded from visiting her daughter who ultimately dies following a tonsillectomy operation. Over the subsequent 35 years, our approach to family support around the time of a child's death has changed dramatically. Active involvement of parents and siblings is encouraged and "standards of care" for these situations have been produced for adult and paediatric practice. Yet despite these changes, accompanied by extensive literature on grief and bereavement,⁶⁻¹⁰ and several books addressing the death of a child,¹¹⁻¹⁴ there is very little scientific research on the role of bereavement follow up.¹⁵ One paper has reviewed the effectiveness of a bereavement programme.¹⁶ It identified only four randomised controlled studies, two of which showed benefit and two that did not. Two of the studies were exclusively perinatal: one dealt with the death of a parent and one with "death within a family". No randomised controlled trials on paediatric bereavement have been identified. One study that prospectively evaluated families following paediatric intensive care identified an increased risk of psychiatric illness.¹

Like many similar programmes, our service has developed haphazardly. The concept that such meetings are a "good thing" is not backed by a clear understanding of which bits are the "good" bits. By reflecting on our work we have tried to identify some of those important elements. We hope that this list will be of value to general paediatricians in practice and in training. Although our experience comes from a PICU, the families described here have all suffered sudden and unexpected loss. The principles of support are therefore applicable to all such situations, wherever the death may occur.

One group of deaths that is not discussed here is infant deaths, including sudden infant death syndrome. This is not a group of patients that we have met with, and poses a particular set of problems. Contact with medical staff will often be extremely brief, making follow up difficult. Many of the principles above remain just as pertinent, but clear local arrangements for relaying the results of investigations need to be explicit.

Because of the nature of bereavement work it is likely that the best training for professionals is to equip them with the background theory of grief and with communication skills,¹⁷ alongside their clinical knowledge of the child's condition. Distressed family members need to feel able to talk to them and ask their questions; staff should be able to respond appropriately. How formal this training should be is unclear, and it will mainly rely on experiential learning. However, clinicians seem to find bereavement issues particularly difficult and