Personal practice

Parents interviewed after their child's death

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Modern medicine demands self audit. The process is rarely flattering, and glaring weaknesses become all too evident. A review of 12 interviews of recently bereaved parents is presented here as such an exercise. The paper will not focus on issues of the bereavement reaction itself, which are well covered elsewhere,¹⁻³ but rather on the broader issues raised by contact with the families after their loss.

Method

This is a study of postmortem contact with families over an 18 month period at Booth Hall and the Royal Manchester Children's Hospitals. The families of all 13 children to die on the authors' service over this time were seen and notes made at the time of the interview. The parents involved were contacted by letter about six weeks after the death of their child inviting them to attend the hospital to discuss postmortem findings or any residual worries they might have over their child's last illness. At the time of the death of their child they would have been told to expect this invitation. The interviews were conducted in office surroundings divorced from outpatient or ward activities or, in one case, at the parent's home.

Each interview was structured. The format was: an initial discussion of postmortem findings; relation of these to clinical observations and explanations given at the time followed by any questions; enquiry into current feelings and behaviour of parents and siblings; formal counselling/advice as necessary followed by a word on the future, including the introduction of genetic counselling; then a further question session, and closing with an invitation to make contact as required. The social worker concerned would usually make subsequent contact on at least one occasion, and the family doctor was informed of the essence of the interview content.

A social worker, attached to the Department of Child Neurology and known to the parents, was present at seven of these interviews and made

subsequent contact with four of the remaining six parents.

Reports

Case 1. A boy with tuberous sclerosis had developed a glioma. After treatment he was left blind, intellectually handicapped, and with epilepsy. His tumour recurred, and there had been a steady downhill course over two to three months with an increase in frequency of fits and physical handicap to the extent that he became totally dependent. He finally lapsed into coma and was readmitted. His parents stayed by his side for five hours, but he died while they were away taking lunch.

The follow up interview went as planned, and the family was coping well with its loss. The parents and teenage daughter got up to leave, and then the father asked to have a private word. His daughter and wife having left, he said that although the other two probably did not suspect he knew that we had hastened the demise of his son while they were at lunch. He was not apportioning blame but was obviously feeling angry. The women were recalled and the matter discussed openly, though it is not clear if we were believed.

Comment

Misconceptions, be they about the illness, the death, or the care, can often be dealt with at the follow up interview if not previously discovered. Anger is a normal stage in mourning. It needs a focus, and the medical team becomes that focus because they have failed to cure. This father needed time and counselling to overcome his anger. Anticipatory grieving often includes a rehearsal of the death: how it will come, where it will come, who will be present, how they will react. If the reality does not match the 'rehearsed' scene the family may find themselves ill equipped to cope. Denied the opportunity to be with his son at the end, the father had to transfer the guilt he felt as a result onto others because of the

pain it was causing him. Bereavement counselling then sought to explore and resolve these feelings. Similarly, nursing staff needed to resolve their feelings of guilt at having unwittingly 'spoiled' the event for the family.

Cases 2 and 3. A 7 year old girl and 12 year old boy, both of whom were severely mentally and physically handicapped and totally dependent, died in residential care.

The girl was the only child of a single parent (a student nurse) who became pregnant after coming off the contraceptive pill for medical reasons. She had severe guilt feelings about her child's condition (seeing this as a punishment on her as the child's father was violent and a drug addict). She expressed a wish during the first year of life that the child might die. The child was placed in residential care, and the mother found work away in seaside towns, making periodic visits home to see her daughter. During the last year of the child's life the mother eventually learnt to cope with her daughter's condition and gave up work to look after her. The child received day care but lived with her mother with increasing hospital admissions until her death in hospital. The mother had spent sufficient time at home caring for her child to expiate the guilt feelings she had experienced earlier. Coming back to the hospital after the child's death was an acknowledgement by her of the help given throughout the child's life. It also enabled her to receive the acknowledgement of professionals that she too had played her part in the care of her daughter.

The 12 year old boy died unexpectedly from an overwhelming bronchopneumonia 12 hours after being left for weekend short term care. He had been well when his parents had left him. The hostel staff had transferred him to the local district general hospital, having found him 'collapsed', where he was found to be dead on arrival. The first his parents had heard of this was a call from the casualty officer. Naturally, this had angered them, and this annoyance was mixed up with their surprise and feeling of loss. They also attended to ensure he had not suffered (without them) and to give the hospital team thanks. They needed help unravelling their feelings, and procedural change at the hospital and hostel was negotiated to ensure parents would never learn of a tragedy in this way again.

Case 4. A girl died at the age of 9 months with spinal muscular atrophy. She had been born with arthrogryposis and had absent distal latencies and slowing on motor nerve conduction velocity testing. A tentative diagnosis of an hereditary motor neuropathy was made. The parents were told that she

would be a weak child and would have a short life, which they interpreted to mean a few years. The parents coped well until a few weeks before her death when she became ill just as community support was lacking—both health visitor and physiotherapist were absent—and she was seen by a general practitioner who was not familiar with her history. Consequently, when she was eventually readmitted to hospital she had deteriorated considerably, showing signs of respiratory failure.

The parents were given a new diagnosis—spinal muscular atrophy—but did not comprehend the gravity of her condition until they were told on enquiring that there was no need to take her for a triple vaccination. Even so, they were not prepared for the rapid deterioration that followed and were puzzled by the cause of death. A planned postmortem examination did not take place. The follow up interview provided an opportunity for parents to express anger and puzzlement. The word 'bronchopneumonia' appeared on the death certificate, and while they had been told their daughter had a 'chest infection' they had not equated this with pneumonia.

Social work continues with these parents, who show increased anxiety about the health of their first child aged 4 years and who also have not made any final decision about having further children.

Comment

Avoidance of the words 'pneumonia' and 'death' highlight how important the choice of words is. The best communication arises out of the delivery of simple, truthful facts.

Case 5. A 6 year old boy had developed a cervical myelitis when he was 2 years old. A tracheostomy allowed him to breathe adequately until, tragically, though on an intensive care unit, he suffered respiratory insufficiency one night from either a deterioration in his condition or airways obstruction, and he developed hypoxic cerebral damage. He died four years later from pneumonia, having spent most of the interim at home with local support. The years had not been easy, with fits and self mutilation, which caused great difficulty. The parents felt some anger towards the medical team for having let the hypoxic episode happen. This was tempered by gratitude for the support they received over the ensuing four years. During this time there was close contact with the medical and social work teams, and a full explanation of what happened was given many times. On each occasion concern was soon redirected to the medical problem active at that time.

The follow up interview was conducted at the

parent's home. His initial illness was discussed once more at some length, and the parents were able to clarify their thoughts on the relative contribution of the different factors to his ultimate handicap. His death had been peaceful and they retained no worry over that but rather talked about how to cope with the question of his older brother.

Comment

The interview led to better understanding of the cause of the boy's illness and the nature of his death and counselling on bereavement in all family members. It also acted as a poignant reminder that medical teams may also feel guilt, at times irrationally, about their patients' deaths, and contact with families subsequently may help their feelings too. This case, as in case 13, shows how repeated counselling over some years lessens anger and puzzlement after death.

Cases 6, 10, and 11. In these three cases postmortem findings and their bearing on genetic counselling were foremost in the parents' minds.

The follow up visit after the death of a 6 month old girl with Leigh's encephalomyelopathy was of vital importance to both parents. The success of their relationship had been invested in her—each had divorced to marry after confirmation of the pregnancy.

They were disappointed to learn of a possible one in four chance of recurrence as they were both anxious to have another child as soon as possible. The parents were counselled in the issues involved in 'replacing' a lost child before allowing sufficient time for the grieving process. The mother later acknowledged (to the social worker) the good sense of this advice given by the consultant but nevertheless chose to consider herself immune from further disaster and stated she firmly intended to become pregnant again almost immediately. She would not admit to any negative feelings and threw herself energetically back into the routine of providing a healthy 'good life' environment for her sturdy children from her previous marriage. The children were encouraged to raise money for the hospital and donated £150. The father suffered acutely as his first marriage had been childless. He was more inclined to accept counselling and recognised his wife's energetic commitment to 'good healthy living' as a subconscious attempt to ward off a second tragedy. (The dead child was the result of an adulterous relationship whereas the next child would be conceived within the sanctity of marriage.)

Another couple in their late 30s shrank from the prospect of the recessive inheritance of their child's spinal muscular atrophy, whereas reassurance was

felt by a couple in their late 40s when they learnt about the inheritance of their 7 year old's nemaline myopathy. Their older daughter had been about to get married, and recessive inheritance made the risk of occurrence in her children very small.

Cases 8 and 12. Two cases were involved in requests for donation of transplant organs. An 8 month old boy choked on toast. The hypoxic insult led to brain death some seven days later. The boy's liver was transplanted. The follow up interview covered a lot of ground. The boy's siblings accused the parents of negligence for giving him toast when so young. The parents were supported in this respect. They had fully understood the issue of brain death at the time, which is not always the case. Each of the four siblings was showing behaviour attributable to bereavement according to their age, and the parents were counselled on this. The week before the follow up interview the liver recipient had died. Parents had questions to ask about this, but their dominant feeling was that 'part of their child had lived on', and this had comforted them. A national newspaper had been keen for their story, and they were advised on aspects of this. Contact was subsequently made through the hospital administration department. The newspaper paid a fee for the story, which the parents spent on the surviving children.

A 16 year old girl with a rare form of tyrosinaemia developed an encephalopathy, which led to brain death. Her parents asked if her heart could be donated for transplant. There then followed an agonising 24 hours in which they first faced the prospect of her being moved on her ventilator to London, followed by the decision that she was not suitable as a donor. The news that she was dead on her ventilator was met with an angry outburst, 'Do not be so stupid, of course she is not'. The transplant option having fallen through, the parents agreed only to a postmortem liver biopsy for their revered daughter, and they did not attend a follow up interview. Perhaps they could not face the doctor who had brought the bad news, but they did revisit the ward who had cared for her long term and gave profuse thanks and a donation.

Case 13. A 12 year old boy died of a leucodystrophy, as had his brother. His death was anticipated for some months. His brother had died in a long term mental handicap residence in what his mother had viewed as being undesirable circumstances. A promise was kept to keep her second son in a children's hospital. His care was shared with the family, the child spending part of the week at home, part in hospital. Special school placement and aids in the home were arranged in cooperation with the local

authority and charitable agencies. Social work support continued with counselling for all members of the family at appropriate times. Although death was inevitable, and some anticipatory grief work had occurred, death came suddenly and took both the hospital staff and the family unawares. The parents were seen on the ward shortly afterwards by the consultant and social worker, whose support for the family continued, with bereavement counselling gradually decreasing in the next few months. The offer of a follow up consultation was not taken up by the family as at that time they considered there was nothing further they needed to discuss. However, intermittent contact with the social worker has continued, and the mother has recently raised the question of recurrence, which may lead to a delayed follow up interview to discuss the genetic implications for the two surviving children.

Comment

The protracted nature of the illness gave many opportunities for detailed discussion of the child's condition with the family. The follow up interview, which can be a painful experience for families, was therefore avoided. All the issues may not be clearly thought out when families are still in the early stages of mourning, and it may be found that a family seeks further advice at a later stage when they feel better equipped to cope.

Case 7. A 14 year old girl died after a four month struggle with chronic meningitis. An occipital sinus had been discovered at a fairly early stage and excised. Despite this the pyogenic and chemical inflammatory process was never overcome. The medical team felt some guilt as death from meningitis 'is avoidable'. The parents returned with heart felt, profuse thanks for all we had done.

Case 9. A 6 year old girl had Reye's syndrome, which led to brain death. The parents returned to learn we had excluded a simple genetic condition as far as possible with enzyme assays. They had learnt of the possible aetiological role of aspirin and were fearful of giving it to other family members. Their fears were put in perspective. They were also told of the National Encephalopathy Survey and agreed to help with the research. Their grief reaction proceeded normally, and we were contacted later with thanks.

Discussion and conclusions

There are many issues common to most of the detailed case histories. Some families need no help

from professionals with their grief and are wholly self supporting. When the social worker has been in contact with the family the continuation of her involvement may be brief, checking that support is available and that the family's mourning is taking a normal course. Advice on self help groups, and the offer of follow up if the family feel it would be beneficial, may be the end of her involvement. Where support before the child's death has been of long duration, or intensive, however, her involvement after the bereavement is likely to be for a longer period. The aim is to ensure that mourning is following a steady course toward adaptation to the loss and the resumption of normal life. Opportunities are given to explore the feelings aroused by bereavement, such as anger and guilt, and to attempt to resolve them. If a member of the family has a reaction so intense as to cause break down and the risk of a suicide then more specialised help will be sought for the sufferer through the general practitioner.

The follow up interview provides not only an opportunity for the doctor to participate in the bereavement counselling process but also a forum where communication that previously has been abysmal can be improved. Explanation can be improved on and misapprehension dispelled. One cannot help but feel that litigation might also be reduced if the follow up interview were more widely used. Parents also welcome the opportunity to offer personal thanks. In general practice such a meeting can be easily contrived; in hospital doctors are less accessible. Where a multidisciplinary team is involved an account of the meeting can lead to better team work, changes in practice and procedure, and improved morale.

The main issues raised by the interviews are listed below, and the structure of the interview should encompass each aspect:

- (i) Discussion of the postmortem examination.
- (ii) Re-explanation of the course of the illness in the light of the postmortem examination.
- (iii) Dispensing with misconceptions about illness, death, or care.
- (iv) Alleviation of guilt.
- (v) Counselling on bereavement behaviour of parents and siblings.
- (vi) Offering of advice on management of existing children.
- (vii) Genetic counselling for family.
- (viii) Update on transplant recipient if relevant.
- (ix) Acceptance of thanks, donations, and offers to help with research.

Two recent reports show how postmortem family support in the context of perinatal and sudden infant death can be effective and reduce morbidity.^{4 5} We

consider it should be in the scope of all paediatric departments to extend this approach to all deaths.

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