

## Attitudes of parents and paediatricians to a baby's death

My first child died nearly 50 years ago and that sensitized me to the feelings of people relating to child death. Since then, with necropsies on about 6000 chiefly baby deaths, it has been my practice to talk not only to the doctors and nurses looking after children, but also to the parents. The recent 50 years have seen a great change in the prevalence and causes of child death, and in 'the total expectations of life' and so in attitudes to children and death.

My first experience of many child deaths was during the last war when I was the Senior Resident at the Children's Hospital in Bristol. At that time Bristol was being subjected to air raids. Children were dying almost daily in the hospital from gastroenteritis, tuberculous meningitis and rheumatic fever, and there were baby deaths associated with the air raids, having been smothered under rubble.

At this time there was no treatment for tuberculous meningitis, the child died within 30 days of diagnosis and we attempted to identify the adults with open tuberculosis in families where children had been admitted. Before the child died it was usually possible to identify the person who had given the child the infection. Much is made today of the question of guilt related to baby death. We frequently identified the relative who had in fact killed the child. We were amazed at the virtual complete absence of guilt trauma apparent among the relatives and within the family. Within child deaths, the greatest effects on staff and parents were in children with acute rheumatic fever. This was perhaps because they were older and had been in hospital for several weeks before they died, also they were often extremely pretty children, with very happy outgoing dispositions. The other groups were coeliacs and 'pink disease', who often had months of hospital care before death.

We became conscious of the difference between the effects on parents of the babies dying from air raids and accidents and those dying in hospital from regular diseases. With parents of children who had had accidents, although producing anger against the obvious external forces responsible for death, their later recovery appeared to be uncomplicated and straightforward. This was only obvious in contrast to families with what we call disease death. Our conventional nomenclature concerning deaths seemed to be emotionally wrong. To the ordinary person deaths from accidents, even filicide, are comprehensible and thus are natural deaths from a psychological point of view. Deaths from what we call natural disease are to the layman, and possibly even to us ourselves, only partially explicable. These are psychologically unexplained deaths. This is nothing new as readers of Frazer's 'Golden Bough' will be aware, in many communities the handling of the bodies of people in battle or while hunting was by a different set of persons and circumstances than those with death due to diseases.

When I became a regular paediatric pathologist, I felt it my duty to explain to parents why their children had died. Soon, realizing that often I had not been understood, I attempted to make simpler and simpler medical explanations. I now look back with

amazement on those many hours that I spent doing this and wonder indeed what I was doing. As I became more and more interested in the mechanisms which make diseases progress in one person rather than another and kill one person rather than another, I became less and less arrogant and asked more questions. It became increasingly obvious to me that it mattered little to most parents whether their child died from this or that disease, unless there was a very definite hereditary aspect to the situation. Most parents when a child dies are in a state of extreme confusion; confusion not to do with any medical-pathological process, but confusion in their own thoughts relating to the loss of their child. This has become increasingly more obvious when talking to parents of children presenting as 'cot deaths'.

Since the writings of people such as Bowlby, there has been a tendency to look upon bereavement as a sort of profit and loss account, the more you have, if you lose it the greater the loss - a sort of love balance. But this is much too simple. It may be true in many senses and in husbands and wives, but what many do not realize, is that a very large number of parents have a very indistinct concept of what a child means to them, or why they had the child. Once a child is conceived it takes over, it takes over first the mother and then the family. To many parents a new baby is nothing like what they expected, but is a living force that has taken over their whole life. My conversations with bereaved parents in these latter years have been different from those in the past. The sorts of advice that I used to give are now left in the file. For example, to the question of 'When should we have another child?' - the answer used to be 'wait until you want a child that is not the child who died'. Now no direct answer is given. The parents are gently asked as to why they had the child who died and what they wanted from the child who died. They are often only too keen to talk about this because they have often been wondering themselves and people do not discuss it with them in a neutral way. Most parents say that no one discussed with them the question as to why they should or should not have children and were let down when baby arrived. In these days when every child is either deliberately or deliberately/accidentally planned, one can get books of advice on this or that washing machine or this or that car, but virtually nothing on whether you should have a baby with this or that person, for this or that purpose. Much today is talked about heightened expectancy, of health and longevity for all. When a baby dies that expectancy bubble is burst. But when this expectancy is analysed, except in rare circumstances it is an extremely vague and indefinite thing when it comes to children. In discussion relating to abortion there is often talk on 'how much' the mother wants the baby rather than what the baby is 'wanted for'.

Among the parents of child deaths there are some, particularly mothers, who talk much about their feelings of guilt and anger fantasies and become active members of organizations and speakers at meetings. There is a tendency to look on them as the normal but verbally able. While this is so in many, we are increasingly aware that some of these parents are using these means of working through and out some real guilts. The more usual and normal parent says very little.

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Now, our own attitudes as doctors and nurses to child death.

We, as paediatricians, are probably the worst group of people to help parents or ourselves related to child deaths, not because we are not sympathetic people but by the very nature of our own choice of specialty. Paediatrics is probably the specialty that is least concerned with death, and to some extent it is the anti-death phase of medicine. Paediatricians are a very gentle group of doctors.

I was brought up among a teaching fraternity and it was a standing non-joke that 'schoolmasters are men among boys and boys among men'. While there are notable exceptions, there is no doubt but that the paediatrician is a different animal than many of his adult general colleagues. While paediatricians are adult to their patients, our adult colleagues often treat us as children. In my work on organ development with groups such as neurosurgeons and orthopaedic surgeons, the contrast between the company of such specialists and paediatricians is only too obvious. A feature that I as a morbid anatomist was immediately struck with, and others have observed the same, is the rejection of death as seen in the rejection of the dead body that affects many paediatricians. There are some paediatricians who will not enter a postmortem room and many will go to considerable lengths to avoid touching a child after it is dead.

Paediatricians probably become more involved with their patients and their families than any other specialty. Young housepersons, together with the nurses, identify themselves in a semi-parental relationship with the parents. When a child dies they go through an emotional loss, that is sometimes more than the parents because they often have a greater insight into a child's potential than the parent has. This situation needs to be recognized and cared for. Every paediatrician warns their juniors about family involvement but the parable of the mote and beam is not amiss.

For many years we had a mortuary lady whose job it was to look after the baby for the parents after it had died. This lady made the arrangements for the parents to see the paediatricians and, at any visit her habit was to offer the parents a cup of tea and to talk with them and help them. Over these cups of tea the parents often expressed their feelings. The commonest feeling expressed by parents after their interview was how sorry they were for the paediatricians in that the paediatricians were not able to do more to prevent their child dying. Doctors of all seniority were passing on their sense of loss and inadequacy and guilt to the parents. Paediatricians need help with baby deaths almost as much as the parents themselves.

The emotional relationship between paediatricians and children relating to death is reaching increasing stress in many fields. Stress of the premature intensive care unit and the treatment of cancer are the most obvious, but the same is occurring in chronic

diseases such as cystic fibrosis, congenital deformities and even in child diabetes.

With the increased activity of intensive care units the intimate relationship between children dying and their families and the young doctors is increasing. It may be a factor in the present rapid decline in the numbers of children coming for necropsy from the medical side of hospitals. When a child dies the doctor is often emotionally exhausted. He feels that he has had enough and that the child has had enough, and that all possible has been done. Many of these expressions are given as if emanating from the parents when a doctor says that he did not think an autopsy was necessary on a particular child, 'The child has had enough'.

A comment I had recently from a parent who I visited at home as part of our confidential enquiries on all deaths, was salutary. Her child had died with a malignancy after many months and after many admissions for different types of therapy. The care of this child on the ward as described to me seemed to have been exemplary. The paediatricians and nurses had taken the parents into full confidence and there had been open access to the ward for the mother and family if they had any problems at home. The paediatrician had spent much time talking to both parents and the parents had felt that the paediatrician had become a true friend to them as well as being their doctor. However, two days after the baby died on the ward, both parents were on the ward and talking to the sister and nurses about the child's funeral when the doctor came along. The parents went up towards him to talk with him but he went straight on. They said that they were quite certain that he saw and recognized them but he suddenly decided that he couldn't 'face' them and went on. He could not see them. It was at least a month later when the parents told me. They said that this was the most devastating thing that had happened to them during their contact with the hospital.

My plea is that paediatricians need considerably more help in dealing with themselves with the death of children under their care than they or most of their colleagues realize. As the number of child deaths decrease paediatricians' personal problems increase. That they need this help in no way implies criticism, in fact maybe the reverse, it is paediatricians' very sensitivity to the emotional aspects of the diseases of the children that exposes them. Ideally the good scientific doctor keeps his emotions detached, but paediatrics is more than a science, it is increasingly also an art of family understanding. Its strength carries its own special weakness.

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