Current topics

Sudden unexpected infant death

I Paediatric counselling

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One baby in every 500 live births dies suddenly and unexpectedly. Sudden deaths, the most common kind of death among babies aged between one week and two years, rank third of all infant mortality after perinatal conditions and congenital anomalies,¹ and are among the most distressing and baffling tragedies faced by families, health professionals, and officials. In 1980, of the 3800 postperinatal deaths in England and Wales, 2200 (58%) were referred to a coroner for certification. Of these unexpected deaths, 1200 were registered as sudden infant death syndrome, or as due to a condition associated with cot death, signifying that these deaths were medically unexplained or only in part explained at the initial necropsy.

Impact on parents and siblings

Cot deaths are important not only statistically, but also because of the traumatic nature of the bereavement.²⁻³ Parental grief over the poignant loss of an apparently normal child is compounded by shock at the unexpectedness of the disaster, bewilderment, and self blame, which may be severe and longlasting as parents agonise over whether the death might have been prevented. With good support many parents come through with greater maturity and stronger relationships, but for others tension and unresolved grief may cause psychological problems⁴ and can threaten marital harmony,⁵ which may lead to separation, divorce, and even suicide. In addition relationships with grandparents, and surviving and subsequent children, may be disrupted.

Siblings also grieve⁶ but often show it in different ways, so that parents may need help in understanding their children's reactions and behavioural problems. Very young children require more reassurance than usual that they are loved, and older children may themselves need explanation and counselling appropriate to their level of comprehension.

Bereaved families' needs

Families look for understanding comfort and practical help from those close to them, and in some cases from their minister of religion. They need tactful assistance and information about the procedures to be followed from any officials present at the time of death, such as ambulance and hospital casualty staff, the police and coroner's officer, and funeral directors. The most important need is opportunity to talk about the experience with someone who is compassionate and informed about babies and sudden infant deaths, who can explain the necropsy findings, dispel misapprehensions, help restore relationships in the family, and rebuild parental confidence.⁷⁻⁸

Role of the primary care team

Most parents will expect their general practitioner, health visitor, or midwife to give immediate support, and many particularly appreciate reassurance from someone who knew their baby. For a variety of reasons, however, this support is not always forthcoming or sufficiently helpful. Some general practitioners and health visitors do not hear of the death immediately (if, for example the baby is rushed into hospital); some do not appreciate the need for early contact, others help only briefly, finding it difficult to face their own painful emotions of shock, sorrow, and inadequacy—particularly if they had recently been consulted about the baby's health; and few are able to keep abreast of research into this comparatively rare kind of tragedy, which is likely to occur only once every three to five years in a small group practice. Many general practitioners are, however, willing to share the load of counselling with a paediatrician who takes a special interest in this.⁹

A paediatrician's counselling role

There are many ways in which paediatricians may be of help. They can assist with the immediate management of families whose babies are brought dead or dying to an accident and emergency department (if the paediatrics department is on the premises) by liaising with the accident and emergency consultant and staff. Guidelines for accident and emergency departments on the management of unexpected infant deaths are available free from the Foundation for the Study of Infant Deaths.

They can explain necropsy findings and counsel parents who are not registered with a general practitioner, or whose general practitioner would like this cooperation. This requires liaison with the community health staff or family doctor. Most parents are grateful for advice on normal reactions to grief, and many want to be reassured about the health of their surviving children and given guidance about explaining death to them. Paediatricians can help by being prepared to receive any feelings of anger harboured against the general practitioner and by giving reassurance about blame or guilt, which can help restore parental confidence in the primary care team.

They should make themselves available for counselling a few weeks after the death when parents, less shocked, want to ask further questions and discuss future children and the risk of recurrence. Some paediatricians contact the family doctor or parents when the results of the histological tests are known: one suggests that parents make an appointment which they can feel free to cancel if they do not want it on the day.

Paediatricians may liaise with a local parent support group or the Foundation for the Study of Infant Deaths, who offer personal support on a 'one to one' basis.¹⁰ Over 500 new families a year contact the Foundation and more than half wish to be put in touch with someone who has come through a similar tragedy and is ready to befriend. Selection and matching is carefully considered. Befrienders provide empathy, time, and an opportunity to share experience and emotions, which lessens the sense of isolation and offers hope that people do recover. Some paediatricians recognise how difficult it is for bereaved people to take the initiative and inform the local contact parent who arranges (often by consulting the health visitor or family doctor) for a suitable parent to get in touch; others give the newly bereaved parents the name and address of the local contact or the Foundation.

Most parents wish for help and support with subsequent children. General practitioners, obstetricians, and midwives must recognise the

anxiety felt by parents who have lost a child and should arrange for them to see a paediatrician during the next pregnancy to discuss arrangements for examining the baby when it is born and coordinating postnatal care.

Notification to the paediatrician

The paediatrician needs to make prior arrangements to be notified by accident and emergency staff, by pathologists and mortuary attendants,¹¹ and by a designated doctor, responsible for child health in the community health service who can arrange to be told of any sudden death by the coroners' officer. Some paediatricians also make sure that the police, coroner and his officer, ambulance staff, general practitioners, and health visitors know of their special interest in counselling, and referrals may come from any of these sources. A meeting of representatives of these groups enables detailed arrangements to be made which suit local circumstances.

Relationships with general practitioners, pathologists, and community health staff

Paediatricians may inform general practitioners of their willingness to counsel, through the local medical committee. Some paediatricians, on being notified of a cot death, telephone the individual general practitioner to discuss how best support may be offered; others write to the general practitioner at the same time as to the parents, offering a consultation and enclosing a copy of the Foundation's leaflet *Information for parents following the sudden and unexpected death of their baby*. Some paediatricians attend the necropsy, while others confer with the pathologist about both the initial and later findings. In districts where postperinatal deaths are studied, paediatricians will have to work closely with community health doctors. Visits to the parents' home to obtain a clinical history may, if sensitively handled, be therapeutic, since many parents are pleased to give information for medical research.

Conclusion

Several paediatricians already provide a counselling service for parents unexpectedly bereaved. Their knowledge and accumulated experience provides not only preventive support in a crisis, which may induce psychiatric illness in vulnerable people and shatter parental confidence in more resilient families, but may also contribute to a greater understanding of the reasons for these tragedies.

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II Home monitoring

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There are several reports of long term monitoring of respiration and sometimes of heart rate in relation to the possible prevention of the sudden infant death syndrome (SIDS).¹⁻³ Clearly, whatever the mechanism of death, at some stage cessation of breathing or slowing of the heart will occur. If prolonged central apnoea⁴ (the cessation of respiratory movements), or obstructive apnoea⁵ (the continuation of respiratory movements in the absence of airflow at the nostrils and mouth), or bradycardia (with or without apnoea) is the forerunner of death in SIDS, the early detection of any such event might permit successful resuscitative intervention. In the absence of reliable, inexpensive, and convenient methods for monitoring alveolar ventilation and arterial oxygenation in the home the variables monitored have included respiratory movements and the electrocardiogram (ECG). Monitoring of respiration (or its absence) in isolation may be inappropriate⁶ as there is no certainty that changes in the rate or pattern of breathing initiate the sequence of events which leads to death. Conceivably, breathing movements may continue until the moment of death. The precise order of events has never been recorded, and perhaps no one sequence is invariably responsible. As monitoring for apnoea is fairly cheap compared with ECG monitoring the use of an apnoea monitor alone has sometimes been dictated by financial rather than theoretical considerations.

Sensitive screening methods for detecting infants

at 'high risk' have yet to be devised. Scoring systems⁷ based on discriminate analysis of obstetric and perinatal variables have proved helpful in epidemiological studies but are not sufficiently sensitive for clinical use. Risk is increased for certain clinical groups readily identifiable by the paediatrician, but it is not known whether this increased risk is distributed evenly within each group. Subsequent siblings born to families with experience of SIDS,⁸ and 'near miss' for SIDS cases⁹ have been the risk groups most often included in home monitoring programmes. Infants in the latter category are identified after an episode of pallor or cyanosis associated with limpness and apparent cessation of breathing which had led parents or attendants to believe that but for their intervention death would have occurred. By the time of admission to hospital many such infants appear to have recovered and investigations to exclude infective, neurological, cardiovascular, respiratory, and metabolic causes are negative. Positive results of uncertain relevance include the isolation of a virus from the upper respiratory tract, swallowing incoordination, gastro-oesophageal reflux, or minor electroencephalographic changes. Many investigators^{1-3 10 11} reserve the term 'near miss' for infants in whom investigations are negative—an extrapolation from SIDS, which is defined in part by negative necropsy findings. It is likely that had death been caused by the effects of such functional abnormalities, no specific pathological markers