Contemporary Themes

Welfare of Families of Children Found Unexpectedly Dead ("Cot Deaths")

JOHN L. EMERY

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Summary

Families in whom cot deaths occur are a particularly neglected group. They are subjected to unnecessary psychological trauma as part of the process of the exclusion of unnatural death. Paediatricians should make the welfare of the family units part of their own concern and take steps to help both parents and siblings. It is suggested that possibly the coroner or the general practitioner could make an appointment for the family to see a paediatrician interested in cot deaths. This would do much to alleviate suffering associated with them.

Introduction

Death is a natural event. The death of aged parents or grandparents is accepted as normal, for by this time such people have themselves often become psychologically detached from their relatives. It is curious how attitudes to death have changed with the development of civilization. In so-called primitive society we know little of perinatal deaths, but among adults the natural form of death was to be killed while hunting or in battle; deaths from other causes were unnatural and the bodies shunned. Today our nomenclature is completely reversed. Natural death is due to disease and accidents are unnatural.

During the last war, as a resident of a children's hospital in a city subject to repeated air raids, I was struck by the difference in attitudes of the parents of children who died as a result of air raids or accidents and those whose death resulted from acute child diseases. The parents of children killed by bombs were openly often more tearful but there was no doubt in their personal self-confidence or in their statements such as "When this is over we will have another one." Today the same attitude may be seen in the parents of children who have died as a result of accidents, falling off walls, or running under cars. There is often active aggression against the vehicle or person who killed the child but an uncomplicated acceptance of death. In children who have died as a result of cancer and of gross congenital deformities there is acceptance of the inevitability of the child's death or even relief at death after the question "Why should this happen to our child?" has been clearly asked.

During the past 20 years I have dealt with over 5,000 child deaths, and it has always been my policy to make myself available to parents. This has been combined with an attempt to provide a complete community cover on child deaths. This "open-door" system has been available to general practitioners

whereby a child dying at home can be transferred to the hospital for necropsy. Through the courtesy of the coroner all types of child deaths have been dealt with except homicide. Only a small proportion of the parents of children who die in hospital have been seen, mainly those who have openly made some type of complaint, usually not to the clinician in charge or the nursing staff but to the mortuary porters or administrative staff.

The particular problems of the parents of "cot death" babies were brought to my notice when our chief almoner visited the homes of parents and took histories from a series of 50 cases of cot deaths reported to the coroner.¹ Since that time it has been my policy in such cases to meet the mothers and fathers together about three weeks after the child's death, as this seemed to be the time when the shock of the incident was slightly abated and the parents were able to adopt a progressive frame of mind. The parents are usually referred by the coroner's officer when he gives them the death certificate and are interviewed in an office within the children's hospital. The results of several hundred such interviews and the stimulation of a recently bereaved parent promoted this paper, which largely sets out the outcome of 20 years' work in this field.

Present System of Dealing with Cot Deaths

The coroner is responsible for the protection of the general public in the case of any child found dead or who has died unexpectedly in unnatural circumstances and must establish that death is due to a natural disease and not to a preventable circumstance. In a cot death this involves a brief police investigation.

The sequence of events in a home cot death is usually as follows.

(1) The baby is found apparently dead. (2) He is either rushed to the local hospital or to the general practitioner or the latter is called. Death is confirmed. (3) The parents are told that the doctor cannot give a cause of death and the case will have to be referred to the coroner. (4) A police officer visits the home, inspects the cot and rooms, and makes a preliminary report. (5) If death occurs at home the child is taken to a mortuary for necropsy. (6) The parents are asked to attend the local police station. Here they make and sign a statement. (7) There is a delay of two or three days. (8) After the necropsy the parents are called to an inquest. (9) Immediately before the inquest they usually have to identify their dead child in the local mortuary chapel. (10) At the inquest they attest their previous statement, listen to evidence of identification, and hear the pathologist's report and the coroner's verdict. (11) After the coroner's proceedings they are usually given a disposal certificate but have to go to the registrar if they require a copy of the death certificate for insurance purposes.

The whole of this usually takes place within a week, and during this time the parents are in a state of complete uncertainty. The coroner, as a result of the pathologist's report

(provided this states that death was due to natural causes), need not (and frequently does not) hold an inquest but the parents are asked simply to call at the coroner's office and are given a death certificate by the coroner's officer.

If an inquest is held the Press are present and there is usually a brief notice in the local paper. At such inquests one recognizes an almost constant pattern of relatively young parents, with the mother in black, accompanied by at least the maternal grandmother, all of whom are somewhat stunned. The coroner explains to the parents the cause of death and asks them if they understand it and if they have any questions. The parents usually look up with tearful eyes, nod their heads, and there is a silent trooping out.

In court the coroner and the pathologist give simple, lucid explanations of a child's death but 10 minutes later, out of court, the question is usually asked "What did he die from doctor?" The whole thing, in the case of a natural death, is a macabre seance. Luckily, enlightened coroners are now doing their best to avoid this procedure.

Clinical Situation

The occurrence of a cot death in the family is unexpected and unprepared for and it shakes the confidence of the whole family unit as well as its medical advisors.

Mother.—The mother is utterly confused. She has gone through pregnancy and labour and the baby is there, hers, and normal and she sees herself as a live and fruitful woman. She knows that babies are born deformed and that there are complications of delivery in newborns, but her child has been declared free from all such. She is home from the maternity hospital. She has been a little in awe of her baby but it has been doing apparently well for several weeks and then the baby is found dead. Her confidence in her motherhood has its roots cut. Hers was a normal baby—everyone said so. What went wrong? Self-guilt is inevitable. Did she give the child too much or too little food or fruit juice? Should she have breast-fed more or less? Should she have taken the child to the doctor for the snuffles that her own mother said might be the beginning of his first tooth? Should she have. . . ?

Father.—The father is also confused, though to a less extent than the mother. After experiencing his wife's pregnancy and labour he has seen her flower with a child and seen the family grow around him. These new and immensely important stabilizers of family life are suddenly cut with the unexpected death, and with this the new confidence in himself and his wife are questioned. A crisis such as this can bring couples together but it requires a saint not to wonder if in a cot death there has been some omission on someone's part.

Health Visitor.—Whether at the clinic or at the home she may not have seen the child frequently or recently. If she has seen it often she has found nothing, so did she miss something? If she did not see the child recently would she have seen something if she had made a visit? Was there something that she could have done? The mother's confidence in the health visitor is also called into question. The health visitor up to now has been her child expert. What now?

General Practitioner.—The position of the family doctor in the case of a cot death is quite different from that with other deaths of children at home. In the latter he has usually been working with the parents in treating a chronically ill child and jointly supporting parents and child. With a cot death he is in the same position as the health visitor. If he has seen the child frequently he is as surprised as the parents. If at any time he has delayed in visiting the child he must wonder. If he saw the child recently the inevitable question always arises—should he have been sent to the hospital? The doctor cannot win in such circumstances no matter how good he is. I have often thought it a little sad when I have seen parents change their family doctor after a cot death because the discarded doctor is often one of the best child practitioners in the town, for the very doctors who

are interested in children and who look after them well are often those who do not send them all to outpatient departments.

Aim to Minimize Initial Trauma

The first aim in altering the present situation is to minimize the initial trauma of the coroner's investigation. This can be carried out in several ways.

INITIAL VISIT

Whatever we feel of the psychological dangers to parents from cot deaths undoubtedly a few babies are killed by their parents or others. It is not possible to be certain in what proportion of cot deaths an element of neglect or homicide is present but between 1 in 50 and 1 in a 100 may be a fair estimate.

The initial inquiry, therefore, must be under police control. It has been suggested by some that the initial inquiry could be done by the local health visitor, but this is not realistic as she is already emotionally involved with the situation. Home visiting by the local police or C.I.D., however, is something that sets the locality by the ears.

As the initial study has to be by the police it would seem best done by a policewoman in civilian dress visiting the house in an inconspicuous way and not driving up in a police car. The inquiry should be done by some person who has had some instruction in the problems involved with cot deaths and in children's work. There is no reason why a few specially-trained policewomen should not be available in all urban areas who could be called out to such cases, as occurs in some other special circumstances. It would be of great help also if such policewomen could make their information immediately available to the pathologist so that he does not carry out the necropsy completely "blind."

LEGAL STATEMENT

The legal statement that is now prepared by the coroner's officer, usually in his office, could be more easily and humanely taken by the policewoman on a second, prearranged visit. This statement need not be taken until after the preliminary necropsy findings have been discussed with the pathologist but before the latter makes his report to the coroner.

INQUEST

In most cases the pathologist confirms that death is due to natural causes and in such cases an inquest is not necessary. If a case reaches an inquest, however, the parents, relatives, and neighbours know that the question of unnatural death has been raised. This must be dealt with and also be seen to be dealt with. Occasionally the coroner, out of kindness to the parents, holds an informal inquest in his office. I have sometimes been later asked by parents whether an inquest that has been so held has been a proper one or not, or indeed whether in fact the inquest had been completed. Thus most inquests are not necessary, but if they are carried out they should be formal ones and, if possible, reported in the Press.

WHO DOES THE NECROPSY AND WHERE?

Apart from the availability of greater facilities it would seem best for the babies to be taken to a children's hospital of repute and the necropsy done there by the department and, preferably, in the name of the department rather than in that of an individual pathologist. The recent report on coroners makes suggestions that tend to the same conclusion.²

The practice of transporting bodies to the local police mortuary and the necropsy being done by the local forensic expert may give confidence to the local C.I.D. but with modern news coverage the name of the local forensic specialist is probably as familiar as that of the local lord mayor. This name, associated in the public eye with murder trials and the like, strikes a cold blow to the parents of the child concerned.

REGISTERED CAUSE OF DEATH

The necropsy on an apparently normal child with no clinical history is perhaps the most difficult type of any such examination and requires much experience. What of the results of these examinations? They are bound to depend greatly on the knowledge and experience of the person carrying out the necropsy. In about 1 in 10 such cases something gross is found which accounts for the death, requiring no further detailed examination. In about one-third a sufficiently gross lesion is found after histological and bacteriological examinations have been done that would account for clinical disease and death if the child had been in hospital. In a further third some pathological lesion is found, such as a tracheitis or a fatty change in the liver, indicating that the child was definitely ill at the time of death. Often in such cases oedema of the lungs is found, suggesting that death finally resulted from cardiorespiratory failure, and it is practicable to register deaths in such a way.

Finally, there is a group where the most experienced paediatric pathologist can find no adequate anatomical cause of death. What is the pathologist to do? With the presence of gross diseases there is no problem. In the second group a reasonable cause of death is deduced, but in the final group he is left with a baby with certainly nothing to indicate that death was due to any unnatural cause but, equally, nothing to say why death occurred. He could thus say that the child's death was due to a certain "sudden unexpected death syndrome" or "status thymolympaticus" or "an act of God" or even simply that he does not know. Is it true that he doesn't "know"? He has no histological or virus lesion to show that there is a specific cause of death but he also knows that in the children's hospital at that time the wards had an abnormal number of children with, perhaps, gastroenteritis or with acute bronchiolitis or that these deaths coincide with an epidemic of measles. Furthermore, how much do we really know about causes of death in any children? Even in adults we are hard pressed to know why a person with a known disease dies on any particular day.

In the brashness of my youthful bigotry some 20 years ago I stood by my academic principles and said that such deaths in children were natural, the cause of which I did not know. It was not many years later that I began to have inquiries from my paediatric colleagues about what I had found in a child whose necropsy I had done a couple of years previously. Only then did I find that brothers and sisters of the dead children were being sent to outpatient departments by the general practitioners because the parents were anxious lest these children should have some obscure disease and be liable to be found dead in bed at any time.

Since then, when I have been sure that death was not due to unnatural causes, I have always given a cause of death that the parent can accept. The diagnosis given is not fiction but the most likely one according to the situation concerning that child at the time. In my own files the child is also indexed among many "in hospital" deaths as "cause of death unknown" and my academic integrity retained.

The Registrar General has recently allowed the term "cot death syndrome" to be used. While it seems to be reasonable to permit such deaths to have a supplementary registration such as "cot death" or "sudden unexpected death" I am strongly of the opinion that to register deaths in such a way is a retrogressive step, and for two main reasons. Firstly, it tells the parents that the death is due to a mystery disease of infants. Secondly, if its aim is that of obtaining true statistics of the prevalence of the

situation then the Registrar General is not likely to be well informed. Only a very small proportion of such deaths in the country have necropsies carried out by trained paediatric pathologists (in only three coroner's areas to my knowledge), and what is the value of an uncontrolled diagnosis of nothing found? It seems by far the best to register the deaths as caused by the most likely condition after taking all factors into consideration, not just necropsy findings, and to register the circumstances of death separately.

Support and Healing of the Family

The cause of the child's death, the question of the possibility of neglect on the part of the parents, nurses, or doctors, the question of suffocation, or of cow's milk allergy, or of the latest theory of cot deaths that has been publicized in the Press, and the question of whether the baby suffered and the liability of other children to illness are questions that arise at every cot death, and each requires an answer. The question of future children is raised by every couple. How soon to have other children and are there any special precautions to be taken with other children? These are direct questions. More than these, the mother and family's self-confidence has to be restored and also their confidence in their nursing and medical attendants. The mechanism for giving the family such support is more difficult than appears at first sight.

Who is to give this information and advice?

The first and most obvious answer is the general practitioner. In many cases this is not possible. For reasons mentioned above these deaths often shatter the general-practitioner/patient's mutual confidence. In the series of over 300 cases of cot death in which I have seen the parents I estimate that over a third informed me that they were going to change their general practitioner. Often the parents are frankly accusing their doctor, particularly if he was called and the baby died before he arrived or saw the baby a few days before death and did not refer the child to hospital. Often the parents do not give the cot death incident as the cause of their changing their doctor; they say they were going to do it anyway. A family doctor cannot, however, speak authoritatively on the subject of cot deaths as he is unlikely to have seen more than one case in every 10 years of practice. There is, as has already been mentioned, a strain created by the cot death situation between the general practitioner and the parents, and this usually requires some external help in curing.

The second person who seems likely is the *health visitor*. She, however, is in almost the same situation as the general practitioner and, indeed, health visitors in some of the more densely industrial areas are not looked on with anything like the friendly light that our health departments fondly imagine. With these parents of children usually less than 6 months old it is the midwife, who did indeed bring the mothers through labour, who seems to hold a much higher confidence level than the health visitor.

The *coroner* or *coroner's officer*, while he may interpret the pathologist's cause of death, can barely be called on to give general paediatric or genetic advice and, indeed, the further the family can be kept away from the police aspect of the situation the better.

The *coroner's pathologist*, if he is a paediatric pathologist, is in a strong position to give assurance on the cause of death and absence of neglect, but unless he is very clinically orientated and carries with him something of the authority of a children's hospital department he cannot easily discuss siblings or genetic problems. In any case, unfortunately only a small proportion of these deaths are at the present time handled by paediatric pathologists. A general pathologist is unlikely to have the time or inclination to handle patients and has no paediatric departmental support.

The obvious person to give advice to such parents and, by examining the other children, give support and control to the

whole family unit is the *local paediatrician*. Unfortunately, many paediatricians, while they hear of cot deaths, have little or no experience of them or of the problems involved—though I should emphasize that this does not apply to my own colleagues. We have heard of parents who have asked their paediatricians about cot deaths being brushed off with “We don’t see them,” “the experts argue about them,” “we know nothing about them—” paediatricians who treat children in cots and not in family units. Most paediatricians, however, are very willing to help these families—if asked. The very absence of this type of paediatric family support has led to the formation of self-help groups among parents of children sustaining cot deaths in several countries, and recently one had been formed in Britain and has produced some excellent literature for parents.*

Parent support groups for the families of children with chronic diseases such as cystic fibrosis or spina bifida can be of real help; the families in these conditions need *sustained* help and support. The best help that the parents in cases of cot death can have is that which diverts their energies away from the subject into other directions. Thus such guilds, while devised from excellent motives, are apt to be of more harm than use. Our local answer to this problem has been for the paediatric pathologist to see the parents, but it is not possible to continue this in any extensive way and this has now been superseded by a letter giving answers to the most common questions asked.

This letter has been given to the parents by the coroner’s officer at the same time as he gives them the Death Certificate. The parents are told to take the letter away, read it, and inquire to a specific person at the local children’s hospital if they need

further information. Such a letter has been modified and is used by the welfare committee of the new Foundation for the Study of Infant Deaths.† Such hand-outs, while perhaps helping in the end, do not prevent the present unnecessary trauma to the families experiencing such deaths and are no substitute for the help that could easily be given to the family by an interview with an interested paediatrician. There seems to be no reason at all why the coroner or his officer could not have access to the secretary of some local willing paediatrician and make an appointment for the parents to see the paediatrician at his hospital outpatients department. This would be done with the knowledge of the family general practitioner or instead by the general practitioner himself.

At the present time the cot death or sudden unexpected death of a child is a major problem in childhood care; it affects about one in every 400 children born. As was recently pointed out in a Northern Ireland survey,³ we have a definite concern with the attitude of mind of parents with a fear of a cot death.⁴ While at the moment we are unable to prevent these deaths we could do much to alleviate the family suffering associated with them.

References

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- ⁴ *British Medical Journal*, 1971, 4, 250.

* British Guild for Sudden Infant Death Study, honorary secretary Mrs. Jean Knight, 28 Ty Gwyn Crescent, Penylan, Cardiff, Wales.

† Foundation for the study of Infant Deaths, honorary secretary Mrs. N. Hunter Gray, 10 Ripplevale Grove, London N1 1HU.

Hospital Topics

Cogwheel Report in Relation to the Smaller Hospital Group

F. J. FAWCETT, R. E. LODER

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Though the first report of the joint working party on the organization of medical work in hospitals (Cogwheel report)¹ has now been implemented in some of the larger hospital groups so far this has happened in few of the smaller groups. With the increasing pressure from the Department of Health for all groups to adopt a form of medical administration along Cogwheel lines it seems opportune to give our personal experience of implementing this type of administration in a smaller group over the past two-and-a-half years and our views on future developments. The group contains a major district hospital and smaller satellite hospitals, a total of 901 beds (non-psychiatric), and has 50 consultants, of whom 40 are principally employed within the group. The recommendations of the Salmon report² have been almost totally implemented within the group by the nursing staff.

Medical Executive Committee, Peterborough and Stamford Group of Hospitals

F. J. FAWCETT, M.R.C.P., M.R.C.PATH., Secretary and Medical Staff Committee Representative
R. E. LODER, F.F.A. R.C.S., Chairman of Surgical Division

Divisional System of Medical Administration

A system of medical administration with divisions and a small medical executive committee was adopted in the group shortly after the opening of a new district hospital. Soon afterwards 15 new consultants were appointed to the hospital staff, and many felt that the meetings of the medical advisory committee were rather cumbersome, with all the consultants present, discussing matters many of which were of little concern to the majority and coming to decisions which were sometimes changed the following month by a more vociferous member of the staff swaying the committee in the opposite direction. It was hoped that by meeting within divisions medical staff with comparable problems could meet together to discuss only the problems that were of concern to themselves and along with a small executive committee meeting at regular intervals could form a more effective administrative machine than the old medical advisory committee.

Future trends are now more apparent. They include area health boards and the development of powerful groups within the hospital environment, such as the new form of nursing administration envisaged in the Salmon report and the increasingly powerful area supplies department. Thus it is