Developing communication skills in medicine

Supporting relatives following a cot death

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Summary

The incidence of sudden infant death syndrome or cot death has decreased by 60 to 70% in the last 10 years. The largest decrease has been following the *Back to sleep* campaign in 1991. The epidemiology of cot death now emphasises its association with poverty and smoking in the home. The compassionate reception of the ‘cot death’ baby and his family in the Accident and Emergency department is the first step in enabling families to come to terms with the grief that the death produces. Accident and Emergency staff can facilitate the early grieving process by an understanding of the family’s needs and the provision of appropriate information.

Keywords: cot death, communication skills

Cot deaths in England & Wales	
Year	Number
1988	1597
1989	1337
1990	1202
1991	1008
1992	531
1993	458
1994	454
From the Office of Population, Censuses and Surveys	

Box 1

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Compassionate, appropriately directed support for the family of a cot death victim in the Emergency department will have a profound positive effect in both the medium and long-term on the family’s mourning process. In order to provide this support, the doctor needs to understand the epidemiology of the sudden infant death syndrome and to be aware of current theories of causation. This knowledge is especially important as the widespread publicity that cot death has received in the media often means that parents are well informed about risk factors and current theories. It behoves the doctor to be at least as well informed, or his ignorance will reduce the family’s confidence in him. Secondly, it is important that the doctor understands the process of mourning so that it may be assisted, not impeded, in the Emergency department.

Epidemiology of cot death

Most epidemiological and research studies use the term ‘cot death’ to mean an infant found suddenly and unexpectedly dead; the term ‘sudden infant death syndrome’ is described as a sub-group of the former in which careful *post-mortem* examination has not revealed evidence of a fatal condition. However, some authors do use the terms interchangeably. In this article I will use the term ‘cot death’, as we are dealing with that aspect of management which occurs before a *post-mortem* study.

There has been a striking reduction in the incidence of cot death over the last few years both in this country and also in Holland, Australia and New Zealand. The number of cot deaths in England and Wales from 1988 to 1994 is shown in box 1. The reduction in each country appears to be related to national campaigns in which parents were given various relevant pieces of advice (box 2).

The UK *Back to sleep* campaign was not launched until the end of 1991 but, as can be seen from box 1, the incidence of cot death was falling before this. There is evidence¹ that information about the hazards of prone infant sleeping was being published in magazines from the end of 1988. The *Back to sleep* campaign has certainly been subsequently associated with a further decline in the incidence of cot death. An interesting and difficult question is whether this was coincidence or whether the campaign had changed parental behaviour. There have been some studies indicating that mothers are changing their babies’ sleeping positions² but there has been little effect on the incidence of smoking. However, it is my experience that families are now aware of the dangers of passive smoking to their children’s health and certainly state that their practice is no longer to smoke in the same room as their children.

With the reduced numbers of cot death following the recent campaigns, there has also been a lessening of the winter incidence peak and the age peak for babies between two to four months. The significance of these changes is unclear. There is considerable evidence demonstrating the association of cot death with poverty and smoking in the home.^{3,4} The known risk factors for cot death are shown in box 3. Families are often aware of at least some of these and may say “It can’t be a cot death because I don’t smoke/he was lying on his back, etc.”

Current theories of cot death causation

Although epidemiological studies show significant associations between risk factors such as prone sleeping position, prematurity and maternal smoking, they do not allow us to understand the mechanism of cot death. Parents desperately want to know why and how their baby died. These questions cannot yet be answered but there have been some useful negative studies. An obvious mechanism to explain the association between prone sleeping and cot death is the possibility that the infant suffered hypoxia or hypercapnia due to impeded breathing in this position. A review of a number of studies investigating this possibility was produced by Johnson,⁵ who concluded that there was no evidence that hypoxia and hypercapnia would become significant enough to cause death in prone placed babies.

Advice to parents
<ul style="list-style-type: none">• do not lie your baby on his front to sleep• do not allow the baby to get too warm• do not smoke in the same room as the baby• seek early medical advice for symptoms of illness in a baby• breast feed if possible

Box 2

Risk factors of a cot death
<ul style="list-style-type: none">• young maternal age• high parity• winter deaths• two to four months old• low birth weight• multiple births• low social class• smoking• prone sleeping

Box 3

Worden’s tasks of mourning
<ul style="list-style-type: none">• to accept the reality of the loss• to experience the pain of grief• to adjust to life without the deceased person• to ‘withdraw’ from the deceased person and form new relationships

Box 4

There is a large literature describing abnormalities in various organ and physiological systems in groups of infants who died from cot death compared to the results from *post-mortem* examinations of infants dying from known causes. These include studies to show that cot death infants have an abnormal immune response with an increased number of immune cells in pulmonary tissue in one study,⁶ evidence of mast cell activation suggesting a role for anaphylaxis in another⁷ and evidence of increased levels of immunoglobulins in pulmonary lavage specimens.⁸ Another study has shown histological abnormalities in diaphragm muscle suggesting early fatigue of the diaphragm in susceptible infants⁹ and a further study has shown underdevelopment of nephrons in cot death victims’ kidneys.¹⁰ These seemingly unrelated abnormalities together suggest that infants who die from cot death may not be the completely healthy babies they had appeared. This emphasises the extreme importance of a thorough *post-mortem* examination conducted by an experienced paediatric pathologist (*vide infra*).

The process of mourning

It is now understood that unresolved grief can be important in the development of certain psychiatric and especially psychosomatic illnesses.¹¹ The effect of a cot death increases the risk for families in several aspects, including the suddenness of the death, the lack of any explanation for the death, and the fact that the death is of an infant for whom there is such expectation.

The initial reception and the management of the infant and family in the Emergency department can profoundly hinder or advance the mourning process for the bereaved family. It is therefore useful that the doctor attending such a family in the immediate crisis should have an understanding of the process of mourning so that he can facilitate those aspects which are germane to the crisis situation.

Most workers in the field of grief and mourning have identified three of four phases through which bereaved persons pass. They may be of greater or lesser severity or length in individual persons. Psychiatric morbidity is sometimes associated with an individual’s inability to pass through the various stages of grief and mourning. Engel,¹² working in the 1960s, described three phases; denial and disbelief, developing awareness and, finally, resolution. Kubler-Ross, whose book *On death and dying* was the result of a long study of the mourning process, also describes similar stages of denial; rage and anger with depression and finally acceptance. Bowlby and Parkes (the former recognised and influential for his theories on parent–child attachment) describe an initial stage of numbness followed by pining for the lost person and disorganisation in the bereaved and finally a stage of reorganisation. As described by Couriel in *Paediatric support in sudden infant death*,¹³ Worden suggested four tasks that must be undertaken by the bereaved before they can reach a state of acceptance of the death (box 4). The first stage of the mourning process and the first two of Worden’s tasks can be facilitated or hindered in the crisis situation in the Emergency department. These aspects are that the bereaved family accept the reality of their loss by having time, space and support to see, touch and hold their dead baby and if they wish, to bathe and dress him. Secondly, the expression of the pain of grief can be accepted and encouraged by compassionate and supportive care from Emergency department staff.

Practical aspects of care

It is usual for a warning to be received from the Ambulance Service by the Emergency department informing them of the arrival of a cot death infant. It is usual for the baby to be receiving at least basic life support and in some instances advanced life support from the paramedic team. Clearly, at this stage, the situation is unknown and a diagnosis of either death or the possibility of cot death, although likely, is not clear. It is therefore appropriate for resuscitation to continue in the department’s Emergency room. It is often very clear that the infant is dead and has been for some time, as shown by coldness to the touch, stiffness and *post-mortem* lividity. Under these circumstances it would not be appropriate to continue efforts at resuscitation. However, sometimes the situation is not so clear and resuscitation should continue in the usual way.

EXAMINATION/INVESTIGATION OF THE INFANT

After resuscitative efforts have ceased, the infant should be thoroughly examined by a visual inspection. Note should be taken of the baby’s state of

nutrition and any external marks such as bruises. These should be carefully documented and distinction should be made in the documented notes between those marks known to have been caused by the resuscitative efforts, eg, needle punctures and those present prior to resuscitation.

Several investigations will be useful for the pathologist. These include cultures from nasopharynx, nares, stool, urine or blood. A urine sample obtained by suprapubic aspiration can be frozen and sent for metabolic screening. Similarly, a small skin sample can be removed and placed in culture medium. Skin cells will remain viable and can be used for the identification of inborn errors of metabolism.

However, while the investigations are extremely useful and may gain information which would otherwise be lost if the *post mortem* was delayed, nevertheless, individual coroners may take the view that all such investigations should be left to the pathologist. Doctors are advised not to undertake any *post mortem* investigations without prior agreement as to a protocol from their local coroner.

FACILITIES FOR PARENTS

Every Emergency room should have a comfortably and informally furnished room for the use of distressed relatives. The room should be in or close to the 'major area' of the department and it should have a pay-phone facility.

Ideally, at this stage, an experienced nurse should be assigned to the family to be a link for them during the time they remain in the Emergency department. On occasions, other serious events in the department and the changing of shifts may make this very difficult but parents often express in retrospect their gratitude at having someone to explain procedures, accompany them to see their baby again and to just be there and listen at such a time.

BREAKING THE NEWS

The fact that their baby is dead is often known to parents even before arriving at the hospital. However, hope often continues until a formal announcement. Even then, acceptance of the reality of death is a process requiring some time and can be much helped by the words, actions and attitudes of Emergency department staff. The doctor who breaks the news to the family should be as senior as possible, ie, registrar or consultant. It is important that he is not interrupted by the demands of further emergencies while speaking with the parents.

The appearance of the doctor in the parents' room will be a signal to them that information is about to be forthcoming. There is therefore only a few seconds for the doctor to establish a caring professional relationship with the parents. Make sure that you know the parents' names and that of their baby. I have found that brief, non-invasive physical contact is helpful. Therefore I clasp each parent's hand while introducing myself and then sit down. Gentle honesty is the key to breaking the news. I usually use words such as 'I am sorry to have to tell you, but despite everything we could do, your baby Jason is dead'. Delivered in a sympathetic voice and with a caring manner, these words leave the parents with no lingering and confusing false hope, which may be engendered by phrases such as 'Matthew has slipped away'. 'He has gone to another place'. Parents will then often turn to each other and weep. They then often start to express ideas of disbelief, confusion or anger such as 'I can't believe it. He took his bottle at six o'clock'. 'It isn't true'. 'Why didn't the doctor notice something when he had his check-up yesterday?'.

At this point, parents often want to talk about the time leading up to the discovery of the baby. This is therefore a useful time at which to take a detailed history, which is necessary for the pathological diagnosis, and to start to help the parents cope with their feelings of guilt by firmly assuring them that no action or inaction of theirs was a direct cause of the baby's death. As the history unfolds, and if the baby was clearly well or only trivially unwell over the previous two or three days, it is often appropriate to tell the parents that in your opinion it is likely that the baby has been a victim of the sudden infant death syndrome. This gives an opportunity for pointing out that a *post mortem* is a legal requirement and is in everyone's best interests so that any understandable cause of the baby's death can be identified. I have never known parents disturbed about the possibility of a *post mortem*, I think because their need to know 'why?' is overwhelming. There is also a need to know 'how?' Parents may express distress at the thought of their baby being unwell and them being not aware of this, or of their baby showing some symptoms that, had they been alert to, they could have attended to and thus prevented this outcome. It is therefore often appropriate to say that, in cot death, there appears to be no evidence of pain, abnormal movement or distress in the infant.

This session usually takes 20 to 25 minutes. After this time the parents have usually had answers to some of the questions and understood that others are unanswerable, certainly at this time. At this stage the parents should be invited to spend some time with their infant.

TIME WITH THE BABY

As described above, the importance of the family grasping the reality of the infant's death cannot be over-emphasised. The death has been so sudden and unexpected that its unwelcome reality is difficult to internalise. Therefore, time spent with the dead infant, particularly holding and touching him, is instrumental in forwarding the healing process of mourning, although it may appear distressing to others when parents weep and have difficulty in letting go of their baby. Parents and other relatives should be encouraged to spend as much time as they wish with the baby's body. It is useful if they are initially accompanied by their nurse as there may be *post mortem* changes or resuscitation marks that must be explained.

It is very helpful if there can be an additional room in the Emergency department where parents can spend time with their baby. In our department we have such a room between the distressed parents' room and the resuscitation room and although fortunately, this is not often used, it is a great advantage.

Compassion can be shown by the Emergency department staff in the presentation of the baby's body. A little crib or Moses basket with the baby's own blanket or a homely cover takes away some of the clinical appearance. The baby should be dressed in his own clothes (and indeed this may be necessary for forensic examination). The parents can be asked if they would like to wash and re-dress their baby in his own things. Parents later recall such tasks as being very beneficial to their grieving process, by making them feel they were doing what needed to be done for their infant. Clearly, this time must be parent driven and the family must not be hurried away. In some instances parents, particularly young ones, may be reluctant to see their infant. They may have hidden fears of the infant's appearance or be afraid that they will embarrass themselves by a show of emotion. These fears can be anticipated and the parents encouraged to see their infant by being told "he just looks like your baby". Sympathetic support often brings forth tears and their immediate acceptance with compassion encourages the parents to express their distress.

A similar facility should be made available to other relations. Grandparents in particular may experience extreme distress following a cot death. They have a dual grief of the death of their grandchild and their own child's distress. Furthermore, the death of a young infant while they, who may be quite elderly, continue to live, again points to the 'inappropriateness' of childhood death in our twentieth century society.

Older siblings of the baby, particularly those over eight or nine years old, may benefit in the same way as adults from the reality of the experience of seeing their dead baby. However, this is a sensitive area and should only be undertaken with the parents' full acceptance. Younger children have a gradually developing understanding of death, starting from the simple concept of separation. Viewing the body is probably not beneficial for younger children. However, despite their often apparent easy acceptance of their loss, young children require a great deal of reassurance and overt loving behaviour from their parents. This is because they will be experiencing their parents' distress and possibly withdrawal and also because children, particularly from the ages of four or five, may have a 'magical' understanding of death whereby they may think that they have in some way harmed their infant sibling by some bad wish or thought that they had had.

Almost inevitably, the parents or other relatives will wish to return on subsequent days to see the infant again until the body is removed from the hospital. Wherever this may take place, it is important that the surroundings are made as homely and child-orientated as possible with a crib for the infant and comfortable chairs for the family.

COUNSELLORS/RELIGIOUS SUPPORT

Many hospitals have social workers or bereavement counsellors who provide an acute service within working hours and a follow-up support service for bereaved families. It is useful if the contact with the counsellor starts in the acute stage as practical support and advice at this time makes parents receptive to counselling from the same person at a later stage. Similarly, having ascertained the availability of the people involved, an offer of the appropriate religious support should be made.

Checklist for cot death
<ul style="list-style-type: none">• child's name, date of birth, date of death• registrar or consultant spoken to parents• brief clinical history taken• examination/investigations done• parents offered to be with baby• coroner informed• social worker/counsellor informed• general practitioner informed• health visitor informed• minister of religion contacted• advice on registration/funeral given• leaflet from Foundation for the Study of Infant Deaths, given with telephone number of local group• consultant follow-up arranged• social worker/counsellor follow-up arranged• community physician informed• immunisation computer informed

Box 5

Cot death research and support
<p>The Foundation for the Study of Infant Deaths, 14 Halkin Street, London SW1X 7DP, UK Tel 0171-235-0965; Cot Death Helpline 0171-235-1721; fax 0171-823-1986</p>

Box 6

MEMENTOS

Occasionally, parents, when returning for further counselling sessions, express disappointment that they do not have any recent photographs of their baby. Many hospitals therefore take two or three photographs of the dead infant so that these may be given to the parents if such a request is forthcoming. Similarly, hand and foot prints or a small lock of hair would often be cherished. However, mementos should not be taken on an *ad hoc* basis but an agreed hospital policy should be discussed between relevant parties, including lay members of bereavement support organisations.

GOING HOME

Sooner or later the family will want to go home. It is important that their general practitioner is informed as soon as possible so that he can visit the family. In the case of a breast-feeding mother he should be asked to prescribe a lactation-suppressing drug such as bromocriptine. The family should also be aware that once the coroner has been informed, that there is a possibility that the police may visit the scene of the infant's death, but that this is in no way an indication of any suspicion. If at all possible, no distressed person should drive the family home as this is a risk factor for a road traffic accident.

COMMUNICATION

There are many people who need to be informed about the baby's death. We have found that a checklist, which can be attached to the infant's notes, reminds staff of the contacts to be made (box 5).

RELIGIOUS OBSERVANCES

Different Christian denominations may emphasise different aspects at death, but in general there is no particular requirement for special handling of the body. Jewish families usually prefer burial to occur within 24 hours of death. This may cause a problem if the *post mortem* is delayed, but often pathologists are sensitive to this need and will accommodate it if possible. Muslim families may wish to undertake the preparation of the body after the *post mortem* but this may occur at the funeral parlour. In all cases, do not forget to enquire whether any special religious requirement is necessary and consult with the local religious leader if there is a problem.

MEDIUM TO LONG-TERM FOLLOW-UP

As described earlier, because of the nature of cot death, significant medium-term distress and occasional long-term psychiatric problems are to be expected. Follow-up counselling is therefore important but is outside the scope of this article. A useful review is available.¹³

STAFF SUPPORT

Although Accident and Emergency department staff are not unfamiliar with sudden death, the death of an infant is always distressing. This is particularly so for staff who themselves have young infants or grandchildren. Informal discussions allow people to express their feelings, identify good practice and feel renewed for the next occasion.

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