The English Multi-Agency approach to the investigation of sudden unexpected deaths in infancy and the care of bereaved families

Peter J. Fleming

Correspondence to:

Professor Peter Fleming,
Department of Community based Medicine,
University of Bristol,
Level D, St Michaels Hospital,
Bristol BS2 8EG.

Email: peter.fleming@bris.ac.uk
Abstract

Experience of the investigation of unexpected infant deaths in several countries has identified recurring instances of two types of error in such investigations – both equally destructive and undesirable –

i) inadequate investigation failing to identify child neglect or abuse, or

ii) innocent parents being wrongly accused of harming their child.

Studies of the use of multiagency investigation of unexpected infant deaths have shown that the needs of bereaved parents for help and support and the need for statutory agencies to investigate unexpected infant deaths need not be seen as conflicting or incompatible.

The implementation in England of a co-ordinated multiagency approach to the investigation of unexpected deaths in infancy has led both to improved care and support of families and to higher standards in the investigation of such deaths, making optimal use of all available forensic, clinical and epidemiological skills and evidence.

This chapter describes the rationale behind the English approach and the preliminary effects of its implementation over the past few years.
Introduction

The sudden unexpected death of an infant (SUDI) or child is one of the worst tragedies that can befall any family. Bereaved parents expect and should receive appropriate, thorough and sensitive investigations to identify the medical causes of such deaths. Several parallel needs must be fulfilled. Firstly the family’s needs must be recognised - including the need for information and support. There is a need to identify any underlying medical causes of death that may have genetic or public health implications; the legal need for a thorough forensic investigation to exclude unnatural causes of death; and there is the need to protect siblings and subsequent children (1,2,3,4,5). Alongside this, there is the need to protect families from false or inappropriate accusations. Limitations in the previous systems of investigating unexpected deaths meant that some deaths caused by relatives, carers or health professionals were not identified, whilst innocent parents were sometimes accused or convicted of causing such deaths (6,7,8,9).

In England the statutory system for the investigation of unexpected child death was changed with effect from 2008, to include an emphasis on multiagency, multidisciplinary investigation of the death, putting the bereaved family at the centre of the process with respect, care and support from all professionals (10,11,12).

This paper reviews the medical, forensic and sociological literature on the optimal investigation and care of families after the sudden death of a child, describes the
structured multi-agency approach that has been implemented in England and the potential benefits for families and professionals.

Professional responses to sudden unexpected deaths: the balance between care and investigation.

Professional responses to sudden unexpected childhood deaths have several interdependent purposes (12):

i. Providing care, support and information to bereaved families.

ii. Investigating the circumstances of the death and identifying potentially preventable factors or evidence of neglect or abuse.

iii. Collecting and collating information on patterns of causes of death, and identifying potentially contributory epidemiological or environmental factors.

iv. Modifying current practices in medical or social care to reduce the risk of such deaths in the future.

The balance between these purposes varies widely between and within countries. The identification where possible of a cause of death may, in itself be very important in the process of providing help to the bereaved family (1,2,10,11,12,13).
In many countries the professional responses to sudden unexpected deaths in infancy are based upon the investigation of the death and the identification of contributory factors, including abuse and neglect. Care of the bereaved family is commonly not a primary responsibility of the investigating agencies. (1,5,14,15,16,17).

A number of large-scale studies of unexpected infant deaths have shown that for the great majority, neglect or abuse are not important contributory factors (2,3,11,18,19). Thus, although recognition of neglect or abuse and protection of other children must remain a priority, in terms of prevention of future deaths it is of at least equal if not greater importance to identify potentially important medical social or environmental factors (10,11,12,17,18,19).

Thorough investigation of the circumstances of the death may be of great importance in protecting innocent families from later accusations, but an insensitive or inadequate approach to investigation can add significantly to the distress experienced by families (9, 11,12,20). Even where the death is a result of abuse or neglect, the wider family, including any siblings and any non-abusing parent will need support (10,11,12,21,22).

**What investigations are needed?**

Arnestad (16) reviewed SUDI investigations carried out in Oslo, and assessed their relative values in the identification of specific causes of deaths. Of 309 SUDI, 73
(23.6%) were found to be due to specific identifiable causes, (e.g. infections, accidents or non-accidental injuries). In the identification of these causes, the case history was a major factor for 10%, the examination of the circumstances of the death for 42%, and the gross post-mortem examination for 44%. For many the combination of two or more investigations was necessary to make the diagnosis. In a similar study in Australia Mitchell (23) found the death scene assessment was less often informative.

The nature and complexity of the post-mortem examination after SUDI should also be clearly related to the probability of finding an explanation for the death. Various complex protocols have been described (2,3,11,16,19,23,24,25). The public reaction to the past practices of tissue or organ retention has led to a marked reduction in the investigations carried out at post-mortem examination by some pathologists, with a consequent lack of potentially important information on conditions (e.g. metabolic disorders) that may have major genetic implications for other members of the family. The Kennedy Report in the UK defined an evidence based post-mortem protocol for such infants, that balances the probability of obtaining useful information against the needs of parents for the examination to be completed quickly, with a minimum of tissue retention (11).

In a recent study in the UK we found that this multistage multiagency investigative process with an evidence-based post-mortem protocol led to the identification of a higher proportion of the deaths being explained by an identified cause than was the case in a similar study a decade earlier (41% vs 20% respectively) (2,26).
“Circumstances of death” or “death scene” investigation?

Examination of the place and circumstances in which the death occurred is commonly of great value in understanding the processes that may have led to the death, but a static investigation of the conditions at the scene after the event (the “death scene”) is greatly enhanced by visiting the scene with the parent or carer and obtaining a detailed account of the sequence of events that preceded and followed the discovery of the death (the “circumstances of death”).

One difficulty with such investigations is that they are commonly conducted by professionals who visit homes only after an infant has died, and findings that may be social, cultural or economic markers of normal patterns of childcare may be misinterpreted as being causally related to the death. Investigators must have detailed knowledge of normal child development and its variability (e.g. “could this infant have done this?”) as well as variations in childcare practices within a particular community or cultural group. Conversely, without good “control” information (e.g. information on other families in the community), potentially contributory factors that may be of great importance in the aetiology of the deaths (e.g. sleeping position) may not be recognised.

Whilst some hazardous sleeping environments can be identified by death scene investigations, it is dangerous to over-interpret more subtle findings in the circumstances of death without appropriate age, social, ethnic and culturally matched controls (2,26,27,28,29,30,31,32).
Medical or forensic investigation of sudden deaths in infancy?

In the assessment of the possibility of abuse or neglect as a cause of injury or illness in childhood the emphasis over the past 10 years has increasingly been on multi-agency cooperation and joint working practices (10,21,22,30,31,33,34).

A coordinated multi-agency approach has been adopted as the basis for the statutory investigation in England of all unexpected deaths of children (10,32).

In most areas of the UK the police child abuse investigation team is made up of experienced crime investigators, with training and experience in the care of children and families in difficult circumstances and in working with other agencies including health and social care. Police child abuse investigation teams, social services departments and medical carers have developed joint protocols, to ensure prompt recognition of child abuse or neglect, and early investigation and action where appropriate, and as a requirement of recent legislation these protocols have been extended to include a joint “rapid response” investigation of all unexpected child deaths by members of each of the relevant agencies (10).

The English multi-agency approach to the investigation of sudden unexpected deaths in childhood infancy and the care of bereaved families
The approach adopted in England is based upon the practices developed in the former county of Avon and endorsed by the Kennedy Committee in 2004 (10,11,12). It was implemented nationally with effect from April 2008, and has four main components (35):

1. A careful history – taken by a skilled and experienced professional.
2. A detailed and careful scene examination – in the light of knowledge of social and cultural norms for that community.
3. A post-mortem examination – carried out according to an evidence-based protocol.
4. A multiprofessional case discussion meeting (involving all of the relevant professional agencies, including police, health and social care.

**Early strategy discussion.**

As soon as possible after every sudden unexpected infant death a strategy discussion is held, involving the paediatrician, the police child abuse investigation team and the children’s social care duty team. The purpose of the discussion is to share information on what has happened and what is known of the background of family or other household members, and to plan how best to investigate the death and to support the family.

**Joint home visit by police and paediatrician.**

The paediatrician and police officer usually see the family together in the Emergency Department, followed by a joint visit by the paediatrician or specialist nurse practitioner together with a member of the police child abuse investigation team and
the family (or others who were present) to the home or the place where the death or collapse occurred. A full medical and social history is taken, with particular emphasis on recent events and a careful review of the circumstances and scene of the death. This joint interview of the family by police and paediatrician (or specialist nurse) allows each professional to collect information relevant to their own area of expertise, and means that the family only have to go through the process of history taking on one occasion.

Historically, the scene of the death of a baby was approached by police officers as a “scene of crime” and the same rules with regard to preservation of evidence were applied as at any suspected homicide. In developing the Avon protocol, police were reassured that there was no risk of compromise of evidence for any potential criminal enquiry. Nationally the police are now enthusiastic supporters of this approach (32,35).

By visiting the home and seeing where the baby died, both the police and the paediatrician can gain further information, whilst the family are given the opportunity to talk through what happened in detail. The police and paediatrician, but most importantly the primary health care team, who must be contacted and kept informed as soon as possible, provide further support to the family. Families have expressed great appreciation of this co-ordinated approach, recognising the need for police involvement, but feeling that the joint visits have been helpful rather than intrusive (12,32).

Post-mortem examination.
A detailed report on the initial history, the findings from the home or scene visit, and any additional relevant information is given to the pathologist by the paediatrician and the police, before the post-mortem examination to ensure that appropriate and relevant post-mortem investigations are carried out. A full post-mortem examination is conducted to an agreed protocol (2,11). Preliminary information on the post-mortem is fed back to the family, usually by the paediatrician and/or the primary healthcare team, as it becomes available. When major concerns are raised about child protection issues the police or children’s social care may become the “lead” agency, but the paediatrician and primary healthcare team continue their involvement with the family (12).

Multi-agency case discussion meeting.

Finally, 2-3 months after the death, a case discussion meeting is held, involving all professionals who were involved with the family. This gives an opportunity to review the classification of the death, identify any contributory factors (12), debrief those involved in the care of the family, and to plan for continuing support of the family, including informing them of the assessment of the cause of the child’s death. The family are given a plain English written explanation of what is understood of the cause of death and the results of the pathology investigations, and a meeting is arranged for the family with the paediatrician and GP to answer their questions and identify continuing needs for support.

A detailed report of the multi-agency case review meeting is sent to the coroner, and helps inform the inquest, which is usually held sometime later.
This joint approach ensures that all necessary information is collected sensitively and promptly, with a minimum of repetition. The broad experience of normal childcare practices in the community brought by the paediatrician and Child Protection team, reduces the risk of attributing death or injury to normal variants in patterns of child care. The continuing involvement of the paediatricians in research into current child care practices within the community further helps to inform their interpretation of information obtained after infant deaths.

In a recent evaluation of the operation of the new protocols in one English Region (population 5 million) we showed that this approach can be made to work consistently over several years in a large and disparate geographical area, with minimal additional cost and considerable improvement in quality and effectiveness of the investigation and the care of families (32).

**Summary**

The sudden unexpected death of an infant or young child warrants careful, evidence based investigation involving child protection teams, healthcare staff and social services, to include a careful review of the history, examination of the scene of the death, post-mortem examination to an evidence-based protocol, and a multi agency review meeting. The aim is to provide help and support for the bereaved family, to identify where possible the cause of the death, to help prevent further such deaths if possible, and to ensure that future children are protected from avoidable environmental hazards, medical conditions (e.g. metabolic conditions), and abuse.
References


7. Dyer C. Group to review babies’ deaths. BMJ 2003;327: 10


20 Dyer C. Paediatricians did not have duty of care to patient’s mother. BMJ, 2002; 325: 1321.


26 Blair PS, Sidebotham P, Evason-Coome C, Edmonds Mt, Heckstall-Smith EMA, Fleming PJ. Hazardous co-sleeping environments and risk factors
amenable to change: Case-control study of SIDS in Southwest England. BMJ 2009;339:b3666 doi10.1136/bmj.b3666


www.pediatrics.org/cgi/content/full/106/3/e41

