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RESPONDING TO UNEXPECTED INFANT DEATHS: EXPERIENCE IN ONE ENGLISH REGION

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ABSTRACT.

New national procedures for responding to the unexpected death of a child in England require a joint agency approach to investigate each death and support the bereaved family. As part of a wider population-based study of sudden unexpected deaths in infancy (SUDI) we evaluated the implementation of this approach.

Methods: A process evaluation using a population-based study of all unexpected deaths from birth to 2 years in the South West of England between January 2003 and December 2006. Local police and health professionals followed a standardised approach to the investigation of each death, supported by the research team set up to facilitate this joint approach as well as collect data for a wider research project.

Results: We were notified of 155/157 SUDI, with a median time to notification of 2 hours. Initial multi-agency discussions took place in 93.5% of cases. A joint home visit by police officers with health professionals was carried out in 117 cases, 75% within 24 hours of the death. Time to notification and interview reduced during the 4 years of the study. Autopsies were conducted on all cases, the median time to autopsy being 3 days. At the conclusion of the investigation, a local multi-agency case discussion was held in 88% of cases. The median time for the whole process (including family support) was 5 months.

Conclusions: This study has demonstrated that with appropriate protocols and support, the joint agency approach to the investigation of unexpected infant deaths can be successfully implemented.

BACKGROUND

In 2006 the UK government outlined new national arrangements for a joint agency "rapid response" to unexpected childhood deaths and a review of all child deaths.(1-3) These guidelines are a major step forward in helping to ensure that each bereaved family receives a thorough yet sensitive investigation of their child's death, and that professionals from all agencies can respond appropriately when a child dies unexpectedly. Such a response requires extra input from professionals, and concerns have been raised about how feasible this will be.(4)

The joint agency approach has been in place in the Avon area for several years, building on previously well established inter-agency working relationships.(5) As part of a wider population-based study of sudden unexpected deaths in infancy over a 4 year period in the South West of England, we evaluated the implementation of this approach across a large geographic region.

METHODS

The South West Infant Sleep Scene (SWISS) study is a large epidemiological study which recruited families across the South West of England (excluding Dorset) after the unexpected death of their infant between January 2003 and December 2006.(6) The region is a diverse geographical area with a total population of 5 million, stretching more than 250 miles and incorporating large urban population centres, as well as remote rural areas. In preparation for the study, agreement was obtained from all local paediatric teams, the four police forces, and the 11 coroners to operate a joint agency response along the lines of the Kennedy report.(3) It was agreed that this approach would be followed as the standard clinical response for all unexpected deaths from birth to 2 years of age, extending beyond the usual 12 month cut off as it was recognised that, whilst rare, unexpected deaths in the second year of life share many characteristics with those in infancy. Unexpected deaths were defined as those deaths which were not anticipated as a significant possibility by those caring for the infant 24 hours before the death or where there was a similarly unexpected collapse leading to or precipitating the events which led to the death.(7) The approach was not applied to expected deaths from known medical causes, or unexpected deaths where a clear medical cause was immediately apparent (e.g. road traffic accident). If, at any stage of the process, significant concerns were identified that the death may have been caused by abuse or neglect, then the investigation would follow standard police and social services guidelines. The study was approved by the Southwest Multi-Centre Research Ethics Committee and by each constituent Local Research Ethics Committee.

The research team consisted of an administrator providing a single point of contact for notification of deaths from across the region, 2 paediatricians and 2 specialist health visitors. The roles of the specially trained health visitors were to collect data for the wider study, but also to provide care for the bereaved parents, to offer support and advice to local paediatricians and other health professionals, and to fully participate in the local joint agency response. The two paediatricians on the team offered a 24 hour consultation service throughout the 4 years of the project and where possible participated directly in the local joint agency response alongside local police and health professionals.

A communication system was set up to ensure prompt notification of all unexpected deaths. All local contact professionals in the health services, police and coroners' offices, along with all police and ambulance control centres were notified of the study and regularly updated with contact details for members of the research team. The main components of the joint agency approach are outlined in the box.

Main components of the joint agency approach(8)

- Transfer of the infant and parent(s) to an emergency department with paediatric facilities
- Notification to the coroner for all unexpected deaths
- Early and continuing multi-agency liaison
- A thorough history taken by an experienced clinician including a careful review of the 24 hours preceding death
- Examination of the baby
- Immediate laboratory investigations taken in the emergency department
- A post-mortem examination carried out by a paediatric pathologist according to an established protocol
- A joint home or scene visit involving the police child protection team, a paediatrician or specialist health visitor, and where possible a member of the primary care team.
- A final case discussion to collate and analyse all information gathered.
- Feedback to the family following the case discussion

RESULTS

During the 4 year study period we were informed of 157 sudden unexpected deaths of infants aged up to 2 years. Two of these deaths were later confirmed as 'expected' deaths of infants with known life limiting conditions and were therefore excluded from the study. Careful review of various alternative sources of information on infant deaths (including returns to CEMACH – the Confidential Enquiry into Maternal and Child Health, monitoring local press, communication with all coroners in the region, and close contact with the paediatricians and police in the region) identified only 2 unexpected infant deaths that met the inclusion criteria but were not notified to us directly. Thus, as far as we can ascertain, we were notified of a total of 155/157 (98.7%) of all cases in the study area within the research period.

Notification

Table 1 lists the timeliness and completeness of the process of investigation. Of the 155 cases, 136 (88%) were notified to the study within 24 hours. The median time from discovery of the death by the parents to notification at our office was 5 hours in the first year of the study reducing to 2 hours by the fourth year. In 145 (93.5%) cases, multi-agency discussions took place between the local paediatrician and hospital staff, primary care, the local police child protection team and the research team. In 66% of cases this liaison took the form of individual telephone consultations, in other cases it involved a joint meeting in the hospital or GP surgery. In all cases the families were seen initially in hospital by the local paediatric team, either alone or with one or both of the police and members of the research team.

Table 1 – Timing and completeness of SUDI investigations 2003-2006

Process		2003	2004	2005	2006	Total
Ascertainment						
SUDI deaths included	N	32	40*	46	37	155
SUDI deaths missed	N	2	0	0	0	2
Notification of death (n=155)						
Time from discovery of death to notification	Median [iqr]	5 hrs [2-8]	2 hrs [1-4]	2 hrs [1-4]	2 hrs [1-3]	2 hrs [1-4]
Home Visit (n=117)						
Home visits conducted	n/N** (%)	18/20 (90%)	30/32 (93.8%)	38/39 (97.4%)	31/32 (96.9%)	117/123 (95.1%)
Home visits within 24 hours	n/N	9/18	23/30	31/38	26/31	89/117
	%	50%	76.7%	81.6%	83.9%	76.1%
Excluded from visit as per protocol	N	12	8	7	5	32
Reasons for exclusion						
Awaiting ethical approval		4	-	-	-	4
Suspected non accidental injury		4	1	2	2	9
Died out of Region		1	-	1	1	3
Died in Hospital or GP Surgery		2	2	1	2	7
Clear medical cause of death		1	5	3	-	9
Post Mortem (n=138)						
Time from death to post mortem (days)	Median	2 days	2 days	3 days	3 days	3 days
	Range	1-5	0-6	1-14	1-6	0-14
Local Case Discussion Meeting (n=108)						
Time from death to final meeting (months)	Median	5 months	6 months	6 months	5 months	5 months
	Range	3-8	2-8	2-9	1-10	1-10

* 2 further deaths were eventually excluded as expected deaths of infants with known life limiting conditions
** number of home visits conducted / total number where a home visit was deemed appropriate

Home visits

According to the joint agency protocol, a home visit was indicated for 123 cases and was carried out in 117 (95.1%). Home visits were excluded in 32 cases; the reasons for these exclusions are listed in Table 1. The median time from discovery of death to the home visit was 8 hours. In 2003 50% of the home visits were conducted within 24 hours of the death, rising to 84% in 2006. The delays arose mainly because of limited availability of the research team at weekends or bank holidays, though many visits were conducted on Saturdays and Sundays. In the first two years of the study many of the local paediatricians did not feel comfortable to conduct home visits without the support of a member of the research team, whilst in the latter years most felt comfortable to do so, having received support and training in the earlier years of the study. Other reasons for delayed home visits included infants who died after several days on PICU, and families who were staying with relatives after the death.

Autopsies

Paediatric post-mortem examinations were carried out in all cases. This process was hampered by the closure of the one paediatric pathology department in the South West during the course of the study. Autopsies were subsequently performed in 5

other hospitals outside the region. Data on the time of the autopsy were available in 138 cases. The median time to autopsy was 3 days, with a full range of 0-14 days. Feedback from the post-mortem examination was variable: initial verbal feedback of preliminary results either directly to the local paediatrician, to the research team, or through the police or coroner's officer was prompt and effective; in many cases however there were significant delays in receiving the final autopsy report.

Case Discussions

Of the 123 cases for which a home visit was indicated a final local case discussion meeting was held in 108 (88%) cases. In the remaining 15, these were not held because the family lived in another region (3), there were ongoing criminal proceedings (3), there was a clear and sufficient medical reason for the death (3), or because of the logistic difficulties in organising the meeting (6). For those cases where a case discussion was held, the median time to the discussion was 5 months, with a range of 2 to 11 months. The case discussions were attended by a range of professionals (Table 2). Direct feedback to parents was offered to all families after the local case review meeting, and a further meeting with the parents by one or more of the healthcare team (with subsequent written feedback) was held in 96/108 cases (89%), most commonly on the day of the meeting. For a further 4 families who did not wish to have a meeting with healthcare professionals, feedback was given only in writing. Thus 100/108 (93%) families received formal feedback from the meetings.

Table 2 – Professionals present at final case discussions

Paediatrician	100%
Local paediatrician	83%
Research paediatrician	81%
GP	99%
Health Visitor*	99%
Police	90%
Pathologist	5%
Social Worker	12%
Midwife	17%
Coroner / coroner's officer	20%

***Local Health Visitor and/or research Health Visitor**

Time requirements

Reviewing the time involved in responding to an unexpected infant death, we estimated a median of 12 hours of paediatrician's time was required for each death (excluding the long travel times required for responses by the research team to deaths in distant parts of the Region), most of which is concentrated in the first 48 hours following the death (Table 3). This increased on occasion to 16 or more hours in the most complex cases, or when large distances were involved. We have not included the additional time involved for the research paediatrician when visits were conducted jointly with a local paediatrician (mostly in the first 2 years of the study). Thus implementation of such a process will have increased staffing requirements for training and staff development particularly in the early years.

Table 3: Time requirements for the rapid response

Actions	Who	Time (hours)
Immediate	Acute on-call paediatrician	3
• confirm death • history/interview with Police • initial investigations • communications • initial report		
Intermediate	Responsible paediatrician or delegated paediatrician	5
• chair the initial meeting • a home visit • pull together all the information		
Final	Responsible paediatrician or delegated paediatrician	4
• preparation • chair final review • feedback to parents		
	Total per death	12

DISCUSSION

Over a 4 year period in a diverse geographical region, we have shown that it is possible to respond to sudden unexpected deaths in infancy according to the protocol outlined by Baroness Kennedy and *Working Together*.(1, 3) The success of this project rested to a large extent on the enthusiasm of local practitioners, particularly local paediatricians and police officers, backed up by clear processes, robust administration and access to expert advice and support. Both hospital and community based paediatricians engaged with the process, typically taking the initial history in the emergency department, often carrying out the joint home visit with the local police team, and attending the final case discussion meeting.

One of the most crucial elements of this approach was that of close inter-agency working. We were very impressed with the positive working relationships that already existed between the hospital and community based health staff, police, social care and coroners in many parts of the region, and observed these strengthening through the course of the project. In all four police forces, it was the child protection teams who took the police lead in investigating these deaths. This brought the advantage for health staff in working with colleagues who were familiar with multi-agency working, and for parents of relating to plain clothes officers who were used to dealing with sensitive family situations. Although we have not been able to formally evaluate the parents' experiences of the process, throughout the four years of the study we were not aware of any complaints in relation to the joint agency approach. Many families expressed their gratitude to the local teams involved, particularly commenting on the sensitive way in which investigations had been carried out, and the feedback they received on the progress of the investigation. It is our perception that by engaging in a joint agency approach from the beginning, it is possible to pursue twin tracks of a robust investigation into the cause and circumstances of death with a sensitive approach to supporting families in their grief.

One of the main concerns expressed by paediatricians was that other commitments, such as clinics, or having to provide acute hospital cover restricts the ability to carry out home visits. This aspect of the protocol took longest to fully establish, but by the end of the study period we were able to achieve a joint police-health home visit within 24 hours for over 80% of cases. We are aware of a number of places across the country, in addition to the South West, where joint home visits are being successfully achieved. These have involved police child protection teams working with hospital and community paediatricians, specially trained and supported nurses or health visitors, or adopting flexible approaches such as an initial visit by the police to ensure there are no suspicious circumstances followed by a joint visit later in the day. There will be situations, as in our study, where a joint visit is not appropriate, but providing good inter-agency liaison exists, a positive approach can be developed that ensures a thorough investigation and appropriate support for the family.

The final case discussion is an important component of the process that enables the professionals to bring together all the information gathered, interpret the significance of findings in relation to understanding the cause of death and any contributory factors, to review any ongoing support needs of the family and to learn lessons as professionals. These discussions were successfully held in the majority of cases, the main difficulty encountered being co-ordinating the diaries of the different professionals involved. Because of the very heavy workload of the paediatric pathology departments, the final post-mortem reports were commonly delayed, and this contributed to the long delays in holding a handful of the final case discussion meetings. The involvement of the primary care teams in these discussions proved extremely positive given their knowledge of the family and community and their ongoing involvement in family support. Given the constraints on general practitioners, we found the best way of ensuring their involvement was to hold the meetings in GP surgeries over lunchtimes. This strategy proved effective with 99% of case discussions being attended by both GP and health visitor.

This study of the process of the rapid response was part of a wider research project, and this undoubtedly contributed to its success. The local paediatricians were supported by the research team of specialist paediatricians and health visitors. This support in the form of telephone advice, and where possible, working directly with the local practitioners was a significant factor in ensuring the success of the programme. It is our view however that implementation of this approach is possible and can be achieved providing local practitioners understand the relevance and benefits of these processes and appropriate structures and support are in place. The structure of our research team could be seen as a primer model to be used in any Region to set a joint agency approach in motion. Drawing on our experience we would suggest the following are essential components for a successful programme:

1. A central notification system with a 24 hour, single point of contact. Good administration is essential for ensuring close liaison between the different team members and with the family, arranging meetings and appropriate follow up, and tracking results and information.
2. Health professionals who are able to respond rapidly with adequate time and flexibility. Whilst in many cases, it was acute, hospital based paediatricians who undertook the rapid response, the constraints of hospital on-call rotas

mean it is essential to ensure that appropriate cover is provided to enable paediatricians to undertake home visits and attend multi-agency meetings.

3. The involvement of trained detectives who are used to inter-agency working. In our experience, the police child protection units are best placed to respond in this way, being non-uniformed, highly trained, and experienced in joint working in complex and sensitive areas.
4. A high level of training and support for all members of the team. In the latter stages of the programme, the research health visitors directly undertook many aspects of the rapid response. However, this was only achieved through intensive training and support over a 4 year period. The health visitors brought skills and understanding that was complementary to those of the local paediatricians, particularly an understanding of normal child development and parenting and an ability to get alongside and support parents through a very difficult time. In addition they were able to acquire skills in history taking and information gathering. The paediatricians in turn brought highly developed history taking and diagnostic skills, medical knowledge, the capacity to interpret the information gathered and to respond to many of the questions raised by parents and other professionals alike. Many of the skills involved in responding to an unexpected death are extensions of normal paediatric skills, but it was our experience that the local paediatricians and the health visitors required additional specific training, both through courses and through an apprenticeship model of getting involved in individual cases alongside one of the more experienced members of the team.
5. Access to expert advice and support. The two research paediatricians had between them built up considerable knowledge and expertise in relation to sudden unexpected death in infancy, and in turn had access to other specialists in paediatric pathology, genetics and other sub-specialties. Throughout the study period, these paediatricians were able to offer advice and support to the local paediatricians. We would recommend that in each strategic health authority area, at least one paediatrician develops specialist knowledge in relation to unexpected child deaths and is able to offer support to a wider network of general paediatricians.

CONCLUSIONS

Local Safeguarding Children Boards across England are expected to have in place procedures for responding to unexpected childhood deaths. These procedures should help to ensure that each child's death is thoroughly investigated in a systematic and sensitive manner, thus improving the ascertainment of the cause of death and any contributory factors, and minimising any extra distress caused to parents by inappropriate responses. We have demonstrated that such processes can be successfully implemented across a wide geographical region using local resources, with the support of a facilitating expert team. As the requirements have now extended to include responding to unexpected deaths in older children, and to the wider public health approach of reviewing all child deaths, the implications for paediatricians and other health professionals in both acute and primary care trusts are considerable. Our experience in training and liaison with health and police colleagues across the country has subsequently shown that different models have developed, based on the same basic framework, and that joint agency protocols can be implemented. It is clear however that structures for training and support are crucial and that adequate time

needs to be allocated to these processes for them to work effectively. Further work is needed to evaluate these processes as they are implemented across the country, particularly assessing outcomes in terms of diagnosis and understanding of child death, and in support for families.

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Statement of Interests
Peter Fleming was a member of the Kennedy Committee that published the intercollegiate document on sudden unexpected death in infancy. Both Peter Fleming and Peter Sidebotham were members of the working group that helped to draft chapter 7 of *Working Together to Safeguard Children*, the statutory guidance to the Children Act 2004, in which the agreed national approaches to the investigation of unexpected child deaths is set out. None of the other authors have any conflicts of interest.

What is already known on this topic
Health and other agencies in England have a statutory duty to work together in a coordinated standard approach in responding to unexpected child deaths.
Concerns have been raised in relation to the feasibility of this approach
There have been no formal evaluations of this joint-agency approach.

What this study adds
The joint agency approach to investigating unexpected child deaths can be effectively implemented across a wide geographical area.
In order to function effectively, such approaches need commitment from motivated professionals in both health and police services, clear structures and robust administration, training for all those involved, and a high level of specialist advice and support.

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