ORIGINAL ARTICLE

Sudden unexpected death in infancy associated with maltreatment: evidence from long term follow up of siblings

A N Stanton

Arch Dis Child 2003;88:699–701

Aims: To identify any association between sudden unexpected death in infancy (SUDI) and maltreatment within local families.

Methods: Retrospective enquiry and subsequent follow up of all siblings and later births within the families. Full investigation of the circumstances of all unexpected deaths. Setting: Scarborough and Bridlington Health Districts and Trusts, North and East Yorkshire. Subjects: All local families losing a baby from SUDI, 1982–96. Follow up to end of 2000. Main outcome measures: Court judgements and the objective decisions of legally constituted Social Services Case Conferences to place siblings on the Child Protection Register (CPR), or provide equivalent safeguards.

Results: Sixty nine families had 72 unexpected deaths; three families had two deaths, with two families raising maltreatment issues. Three families had other children subsequently put on the CPR, all identifiable as likely problems of maltreatment at the time of the single SUDI. In 64/69 families, no child protection issues were formally raised at the time of the SUDI; 41/64 of these families already had 63 children. Four families were lost to follow up after the SUDI; 52/60 of the remaining families have had 93 more children without objective evidence of maltreatment.

Conclusions: The association of SUDI and maltreatment within families was at the lower end of previous estimates, 3–10%. Child protection intervention is rarely needed, but investigation and follow up for maltreatment is mandatory where apparent life threatening episodes are reported with a second baby, and after a recurrence of apparent SUDI.

Correspondence to:
Dr A N Stanton, Ridge
House, Hutton Buscel,
Scarborough, North
Yorkshire YO13 9LL, UK;
dolores.stanton@talk21.com

Accepted
29 November 2002

Investigations of sudden unexpected death in infancy (SUDI) usually conclude as statements of negatives. An apparently healthy baby dies in the early weeks of life. The history, home circumstances, and postmortem examination give no adequate explanation for the death. The baby and carers are often hardly known by the family doctor or health visitor. There has rarely been contact with a paediatrician or social worker. However, all studies of SUDI show that the risks are far from random, identifying a minority of families with adverse socioeconomic circumstances or even a subculture of deprivation, neglect, and abuse.^{1–2} Therefore, there has been a subjective tendency to categorise some SUDI as suspicious of maltreatment, including fabricated and induced illnesses and deaths—commonly known as Munchausen syndrome by proxy (MSBP).³ Sometimes, the suspicions have been confirmed.^{4–7}

In 1985 Emery estimated the incidence of sudden infant death syndrome (SIDS) being filicide, or child homicide by either parent, as 2–10%.⁸ By 1993, his estimate had risen to 10–20%.⁹ In families with a recurrence of unexpected deaths, he estimated the incidence at 55% (31/57 cases reported).¹⁰ This rate exceeds the balance of probabilities and would justify judicial care proceedings in all such cases. The Third Annual Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) Report used local case discussions and regional multiprofessional confidential enquiries, to estimate the association of SUDI with maltreatment at 8–18% (up to 42/228 cases), depending on the perceived credibility of the carers' report of the terminal events.¹¹ Hobbs *et al* have put the risk at 27% (10/37 cases).¹² Green alleged that fellow pathologists have subjective suspicions in 20–40% of cases.¹³ Meadow has warned against meta-analysis, because the few nationally recognised expert witnesses have tended to include the same suspicious cases, as they report their individual experiences.⁵

None of the previous studies have investigated all babies as they were found dead, and then followed a stable population of their families to identify existing and subsequent child protection issues for all the siblings. In the Scarborough area, all SUDI cases have been investigated since 1982 and follow up of the families continued long term. The present study concentrates on court judgements, on the objective decisions of legally constituted Social Services Case Conferences, usually to place siblings on the local Child Protection Registers (CPR), and on the few families who have lost two babies unexpectedly.

METHODS

In Scarborough from 1982 and in Bridlington from 1986, all SUDI were investigated by one paediatrician, in close cooperation with coroners, police, pathologists, health professionals, and social workers. The methods and early clinical findings have been published previously.¹⁴ An active and largely successful preventive programme was established after 1986.^{15–16} These studies were approved by the local ethics committee. The SUDI were unexplained after detailed history, home investigations, and postmortem examination—that is, meeting the criteria of SIDS, or occurred at home in the course of an acute illness that was not recognised as potentially life threatening, as defined by CESDI.¹¹ Most families were seen during subsequent pregnancies and the babies followed up in

Abbreviations: ALTE, apparent life threatening episode; CESDI, Confidential Enquiry into Stillbirths and Deaths in Infancy; CPR, Child Protection Register; MSBP, Munchausen syndrome by proxy; SIDS, sudden infant death syndrome; SUDI, sudden unexpected death in infancy

routine hospital clinics during the early months of life. All admissions and health issues of child protection came to one Children's Department at Scarborough General Hospital. Scarborough is the centre of a well defined North East Yorkshire Health District and Trust, with about 1600 deliveries each year. Bridlington is the main town for the northern half of the East Yorkshire Health District and Trust, with about 400 deliveries annually. At any time, about 3.0/1000 children were entered on the local CPRs, slightly above the national average of 2.3/1000. Entering children on the CPR involved the decision of a multiprofessional Case Conference, held under the statutory authority of the local Social Services Departments, as consolidated by the Children Act 1989. Maltreatment is defined according to categories involving physical, sexual, and emotional injury, or neglect.

RESULTS

Sixty nine families had 72 unexpected deaths, including one death in hospital. There were 59 deaths in the Scarborough district during 1982–96, and 13 in the Bridlington area during 1986–96. Four deaths involved babies less than 28 days old, the youngest 6 days. Three children were older than 12 months, the oldest 27 months.

The background risk factors were typical of the known statistics for SUDI elsewhere,¹¹ nearly all being categorised as SIDS. Five babies were twins; all were the smaller baby by birth weight. Virtually all babies slept on their fronts until 1991 and the national "Back to Sleep" campaign. Only two SUDI occurred in the last third of the study period 1992–96, neither with maltreatment implications. There were two SUDI in 1997–2000, with no child protection issues identified by the end of 2000.

Families with two unexpected deaths

Three families had two unexpected deaths. Two of these families and, therefore, four deaths raised maltreatment issues.

In the first family, the mother had had a severely dysfunctional childhood, but no recent social worker involvement. The first baby died unexpectedly at 4 months of age, but generated no suspicions. The second child had an alleged apparent life threatening episode (ALTE) at 10 weeks of age, while awake. This and later ALTE were always described as being prolonged periods of pallor, drowsiness, and stopping breathing. The mother did not report this event until 24 hours later, and subsequent in-patient investigations were all normal. The baby died at 8 months of age; a Case Conference had grave doubts about the terminal history, but there was no forensic evidence against the diagnosis of SIDS. The third baby was made a Ward of Court after delivery. Two alleged ALTE quickly followed discharge, uneventfully postponed until 4 weeks of age, to mother and baby accommodation. All investigations were normal and he was fostered. Later, social workers attempted rehabilitation, against medical advice. A third alleged ALTE occurred in a Social Services residential home at 11 months of age, in the mother's care, before the County Court freed him for adoption. Five years later, the mother had a fourth child and the Court accepted a presumptive diagnosis of previous MSBP in freeing him for adoption.

In the second family, the first baby died from SIDS at 7 months of age in the mother's care. After delivery at 29 weeks, birth weight 1.8 kg, he required ventilation for two weeks. There had been two brief hospital readmissions with respiratory symptoms, including an episode in which he was found asleep and cyanosed in his cot, but quickly recovered. No special anxieties were generated. The second baby, birth weight 2.1 kg at 31 weeks gestation, had three hospital admissions with ALTE while in the mother's care, at 3, 8, and 10 months of age. The episodes involved reports of cyanosis, sweating, and altered consciousness, but there was no bleeding from the nose or mouth. Clinical examinations were normal, as were all

investigations, and the family left the area. Local information was transferred, but further hospital admissions followed, with a variety of unusual problems and uncertain diagnoses, the last when moribund at 27 months of age. Specialist paediatric and forensic pathologists failed to ascertain the cause of death and the coroner delivered an open verdict. There have been no more children.

In a third family, the first baby had multiple minor congenital abnormalities and died unexpectedly on a hospital ward, aged 7 weeks. He had had elective surgery 11 days earlier and was no longer being monitored closely. The mother was not on the ward overnight and a nurse discovered the SUDI the next morning. The second child created no anxieties. The third had mild respiratory symptoms and died in his pram aged 12 weeks, on the way home from a routine health clinic visit. The mother's resuscitation attempts were unsuccessful, after the apnoea monitor alarmed. A fourth child generated no worries, under close medical supervision but without social worker involvement.

Families with children requiring protection

Three families had one SUDI and other children who were subsequently put on the CPR, or protected by Orders of a Court.

One single mother was from a family with a strong history of low intelligence, violence, and social deprivation. A Case Conference was held three weeks before her first baby died from SIDS, aged 2 months. Some extra support was provided without avail. The second baby was put on the CPR at birth. After an episode of physical abuse at 3 weeks of age, allegedly by the mother's partner, a voluntary residential assessment was undertaken. Subsequently, the mother coped satisfactorily.

The second mother, from a chaotic family background, was the subject of a Care Order in her teens. Her second child died unexpectedly at 2 months. The first child was later put on the CPR for neglect and made a Ward of Court. The third child was quickly abandoned in hospital and both children were subsequently adopted. A fourth baby, by a different partner, was successfully managed through infancy under a Care Order but later fostered, after emotional abuse.

The third family had previously been investigated inconclusively for child neglect in acrimonious legal circumstances. The mother's second child failed to thrive because of inadequate breast milk intake, but improved after the introduction of solids. With the fourth child, the mother avoided health care support. From a birth weight of 2.7 kg, she progressed with breast feeding to only 3.6 kg at 20 weeks. At postmortem examination, after SUDI at 21 weeks, her weight was a marasmic 3.1 kg (0.4th centile for corrected age being 5.1 kg). The subsequent baby was put on the CPR at birth and weighed weekly in a hospital clinic, as part of the imposed Care Plan. Breast feeding was successful on this occasion. The older children were later also put on the CPR, under different categories of maltreatment, and made Wards of Court.

Families with no child protection issues identified

In 64/69 families (93%), including one family with two SUDI (described earlier), no maltreatment anxieties were ever formally raised. In 23 of these, the SUDI was the first born. The other 41 families had already had 63 children. After the SUDI, four families left the area, each with one thriving child identified, and the subsequent history is unknown. Eight families have had no more live births. The remaining 52 families have had 93 more surviving children, to the end of 2000; 43/52 (83%) of the families used a hospital supplied apnoea alarm monitor for at least one subsequent baby and had regular clinic follow up until it was returned. Most of the other babies were also seen at least once, according to parental preference for specialist review.

DISCUSSION

In 69 families with a SUDI, only two lost babies in circumstances suggestive of maltreatment or MSBP. In both cases, two siblings died. There were no reasons to question the initial diagnosis of SIDS in the first deaths, even in retrospect. Both of the second babies had ALTEs in the early months of life, which might have raised maltreatment issues. Both cases preceded the Beverley Allitt murder trial in 1993, which brought MSBP to legal and public attention.¹⁷ For the future, ALTEs after a first SUDI or a second unexplained death in a family must generate a full police and Social Services child protection investigation.

Since 1991, there has been successful publicity for the government's "Back to Sleep" campaign and a sudden and sustained drop in the incidence of SIDS nationally and locally (the United Kingdom SIDS rate was 0.57/1000 live births in 1999). With triple the SIDS rate in the 1980s (when virtually all the present study deaths happened), Emery estimated 50 recurrences each year in England and Wales.¹⁰ If his estimates were correct, for recurrences and filicide,^{8,9} maltreatment might explain a considerable minority of SIDS cases. The present study suggests that his and other estimates may have been too high.¹¹⁻¹³ There is no evidence that the fall in the overall SIDS rate has increased the relative proportion of the minority who have been allegedly maltreated. Excluding the four families not followed up after their SUDI, four unexpected deaths in two local families (4/68 SUDI) can be considered a 6% rate of suspected non-accidental death, but equally implies that 63/65 families (97%) have suffered tragic losses and should not be further burdened by the suspicion of killing the mourned babies, at least in our present state of knowledge. There was detailed evidence available at the time of the SUDI event to predict the need for maltreatment proceedings in the three families where this happened later. There was never any evidence that these SUDI were non-accidental, except as the ultimate penalty for varying degrees of neglect. Such neglect is a child protection issue, and including these three families as part of the spectrum of maltreatment brings the association with SUDI to 5/65 families (8%) or 7/68 deaths (10%).

There were several other families in which anecdotal evidence suggested that the parenting was less than ideal and that the history of the terminal events of the SUDI might have been fabricated, as postulated by the CESDI Report.¹¹ In no case was the immediate veracity of the carers significantly modified by later detailed investigation of the deaths or the long term follow up of the families. The dramatic drop in the

number of SIDS cases locally, after 1986, with "Keep Cool, Baby" advice,¹⁵ and both locally and nationally since 1991, with the "Back to Sleep" campaign,^{11,16} suggests that virtually all carers can and will successfully follow simple advice, however socially, economically, and educationally disadvantaged they may be. If there are maltreatment issues raised by a first SUDI, they must be addressed and a clear Care Plan agreed with the parents. Otherwise, families require compassion after their loss and support for subsequent siblings. Comprehensive child protection investigation can be reserved for the few.

ACKNOWLEDGEMENT

The study could not have been completed without the secretarial support of Mrs E Carruthers.

Author's affiliation

A N Stanton, Consultant Paediatrician, Scarborough Hospital, Woodlands Drive, Scarborough, North Yorkshire YO12 6QL, UK

Retired: May 2001

REFERENCES

- 1 **Roberts J**, Lynch MA, Golding J. Postneonatal mortality in children from abusing families. *BMJ* 1980;**281**:102-4.
- 2 **Oliver JE**. Dead children from problem families in NE Wiltshire. *BMJ* 1983;**286**:115-17.
- 3 **RCPC**. *Fabricated or induced illness by carers. Report of the Working Party of the Royal College of Paediatrics and Child Health*. London: RCPC, 2002.
- 4 **Southall DP**, Plunkett MCB, Banks MW, *et al*. Covert video recordings of life-threatening child abuse: lessons for child protection. *Pediatrics* 1997;**100**:735-60.
- 5 **Meadow R**. Unnatural sudden infant death. *Arch Dis Child* 1999;**80**:7-14.
- 6 **Stanton J**, Simpson A. Murder misdiagnosed as SIDS: a perpetrator's perspective. *Arch Dis Child* 2001;**85**:454-9.
- 7 **Egginton J**. *From cradle to grave*. London: W. H. Allen & Co., 1989.
- 8 **Emery JL**. Infanticide, filicide and cot death. *Arch Dis Child* 1985;**60**:505-7.
- 9 **Emery JL**. Child abuse, sudden infant death syndrome, and unexpected infant death. *Am J Dis Child* 1993;**147**:1097-1100.
- 10 **Wolkind S**, Taylor EM, Waite AJ, *et al*. Recurrence of unexpected infant death. *Acta Paediatr* 1993;**82**:873-6.
- 11 **DoH**. *Confidential enquiry into stillbirths and deaths in infancy. Third annual report*. London: Department of Health, 1996.
- 12 **Hobbs CJ**, Wynne JM, Gellertie R. Leeds inquiry into infant deaths: the importance of abuse and neglect in sudden infant death. *Child Abuse Review* 1995;**4**:329-39.
- 13 **Green MA**. Time to put "cot death" to bed? *BMJ* 1999;**319**:697-8.
- 14 **Stanton AN**. Overheating and cot death. *Lancet* 1984;ii:1199-201.
- 15 **Stanton AN**. Avoiding overheating and preventing cot death. *Lancet* 1991;**338**:1144.
- 16 **Stanton AN**. Trends in sudden infant death. *BMJ* 1995;**310**:1603.
- 17 **Clothier C**, MacDonald CA, Shaw DA. *The Allitt Inquiry*. London: HMSO, 1994.