Major epidemiological changes in sudden infant death syndrome: a 20-year population-based study in the UK

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Summary

Background **Results of case-control studies in the past 5 years suggest that the epidemiology of sudden infant death syndrome (SIDS) has changed since the 1991 UK Back to Sleep campaign. The campaign's advice that parents put babies on their back to sleep led to a fall in death rates. We used a longitudinal dataset to assess these potential changes.**

Methods **Population-based data from home visits have been collected for 369 consecutive unexpected infant deaths (300 SIDS and 69 explained deaths) in Avon over 20 years (1984–2003). Data obtained between 1993 and 1996 from 1300 controls with a chosen "reference" sleep before interview have been used for comparison.**

Findings **Over the past 20 years, the proportion of children who died from SIDS while co-sleeping with their parents, has risen from 12% to 50% ($p<0·0001$), but the actual number of SIDS deaths in the parental bed has halved ($p=0·01$). The proportion seems to have increased partly because the Back to Sleep campaign led to fewer deaths in infants sleeping alone—rather than because of a rise in deaths of infants who bed-shared, and partly because of an increase in the number of deaths in infants sleeping with their parents on a sofa. The proportion of deaths in families from deprived socioeconomic backgrounds has risen from 47% to 74% ($p=0·003$), the prevalence of maternal smoking during pregnancy from 57% to 86% ($p=0·0004$), and the proportion of pre-term infants from 12% to 34% ($p=0·0001$). Although many SIDS infants come from large families, first-born infants are now the largest group. The age of infants who bed-share is significantly smaller than that before the campaign, and fewer are breastfed.**

Interpretation **Factors that contribute to SIDS have changed in their importance over the past 20 years. Although the reasons for the rise in deaths when a parent sleeps with their infant on a sofa are still unclear, we strongly recommend that parents avoid this sleeping environment. Most SIDS deaths now occur in deprived families. To better understand contributory factors and plan preventive measures we need control data from similarly deprived families, and particularly, infant sleep environments.**

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Introduction

The many characteristics and risk factors associated with sudden infant death syndrome (SIDS) are consistent enough for it to have been described as an epidemiological entity.[1] Many researchers have investigated these deaths, with broad agreement on epidemiological findings.[2] Most SIDS deaths happen within the first 8 months of life, with most around 3–4 months and fewest in the first month. The risk is higher for males, pre-term and low birthweight infants, and those sleeping in non-supine positions.

SIDS is defined as the sudden unexpected death of an infant (aged younger than 1 year), for which a post-mortem examination to an agreed protocol, and a review of the clinical history and circumstances of death failed to offer a sufficient explanation.[2–4]

The syndrome is seen in all social groups but is more prevalent in the socioeconomically deprived. Features common to such groups in the population—such as mothers who smoke, young mothers, and large families—are all associated with an increased risk. Since the UK's "Back to Sleep" campaign in 1991, which encouraged parents to place their infant to sleep supine, the number of deaths from SIDS has fallen by 75% in England and Wales.[5]

Results from cross-sectional studies[6–9] show changes in the prevalence of factors associated with SIDS, although collective interpretation of these changes is made difficult by differences in study design. Longitudinal data are gathered nationally in several countries but are limited to basic demographics, and, in the UK at least, these are complicated by inconsistent diagnoses of SIDS.[3,10,11]

In the UK county of Avon, paediatricians have since 1984 interviewed the family at home as soon as possible after all sudden unexpected deaths in infancy (SUDI). SUDI deaths include some explained infant deaths but most are unexplained, and thus meet the definition of SIDS.

We recorded factors affecting infants' sleeping environment. Our investigation also included a postmortem examination by a paediatric pathologist, and multiprofessional meetings to determine the classification of the cause of death.[2–4] We used a comparison group of population controls from a national case-control study of SIDS infants done between 1993 and 1996.[2,10]

Methods

Participants

Avon includes the former Health Districts of Bristol and Weston, and Frenchay and Southmead, and equates to

the former Avon Health Authority area. Avon's population between 1984 and 2003 was about 800 000–900 000 with around 10 000 livebirths per year. Avon includes both rural and urban areas, with both wealthy and deprived areas.[12] The population is predominantly White, with 3–4% of ethnic minorities.

The age-matched control infants from the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) case-control study of SUDI (1993–96), which included Avon,[2] closely matched the socioeconomic status of mothers in the South-West Region with one dependent child as recorded in the 1991 census data.[13] These 1300 CESDI control infants have been used only to show approximate demographic characteristics and practices within the sleeping environment of the average population during a period around the midpoint of the present study.

The Central and South Bristol Local Research Ethics Committee approved these studies.

Procedures

The study was established in January, 1984, to investigate all unexpected deaths of infants (from birth to 1 year of age). We designed a standard protocol, with all unexpected deaths being reported to the study team as soon as possible (usually within 4 h). Families were interviewed by a member of the study team in the emergency department and at home, within 24 h of death, to obtain a detailed history of the infant's medical and social history, family history, social circumstances, and events leading up to and circumstances of the death.

The home visit by a paediatrician, with or without a research Health Visitor included a careful review of the circumstances of death including a detailed description of how the infant was put to sleep and in which position the infant was found. This information was shared with the paediatric pathologist before the post mortem examination.[2–4] Cases were reviewed after 2–3 months at a multiprofessional meeting (including members of the primary health-care team, paediatrician, pathologist, and police) to assess the cause of death and identify any potentially significant contributory factors, as well as planning further support and care of the family.[2–4,14] The study team worked closely with primary-care teams in providing support, care, and information to the family, and with the Coroner's Officers and Police Child Protection team.[2–4]

Unexpected deaths were defined as those that were not expected in the 24 h before the death or before the collapse that led to death. Thus, infants who collapsed and were resuscitated, but later died after being in intensive care, were included in the study.[2]

Throughout the study, the cause of death was assigned at the multiprofessional review meeting. Potentially contributory factors were classified according to the Avon clinicopathological guidelines.[2–4,14]

Deaths were only attributed to accidental overlying (ie, a parent lying on top of the infant) or asphyxiation by the case-review meeting (and thus excluded from the SIDS definition) when the evidence on balance of probability (including histopathological findings, review of history, and death-scene investigation), showed such a cause. Potentially identifiable data were categorised and then removed before entry into the database, which was thus made anonymous before analysis.[15]

The social class coding was based on the Registrar General's occupational coding. The Townsend deprivation score for each postcode is derived from the distribution of normalised socioeconomic indicators within the UK population. The score meant we could identify from the anonymised database infants who lived in the 10% most deprived areas in the South-West of England (equivalent to a score of $+4\cdot44$ or above).[16]

Single mothers included only those who did not live with a partner. Factors in the infant sleeping environment relate to the final sleep of the infants who died or the "reference" sleep of the controls (in the 24 h before the interview).[2] Solitary sleepers were defined as those infants who slept alone for the last or reference sleep, bed-sharers as those who slept with an adult in a bed, co-sleeping as those who slept with an adult in a bed or on a sofa. When dichotomising factors, the lowest quintile of a distribution was chosen if a universal cut-off was not available.

Statistical analysis

Non-parametric distributions were described with medians and interquartile ranges. The Mann-Whitney *U* test was used to test whether two non-parametric independent samples were from the same population. Confidence intervals for death rates were calculated as incidence rates per 1000 births. Confidence intervals for proportional changes in factors were calculated with the Wilson Method. The χ^2 test with Yates's correction was used to test dichotomous differences. The linear χ^2 test for trend (1 df) was used to test for any changes in factors over 5-year intervals.

Role of the funding source

This study was funded by the Foundation for the Study of Infant Deaths (FSID), Babes in Arms, the Confidential Enquiry into Stillbirths and Deaths in Infancy, Action Research, Cot Death Research and Support, and the Charitable Trusts for United Bristol Hospitals. None of the funding organisations was involved in the study design, or data collection, analysis, or interpretation. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

Between 1984 and 2003, the study team were notified of 369 unexpected infant deaths, and a careful review of

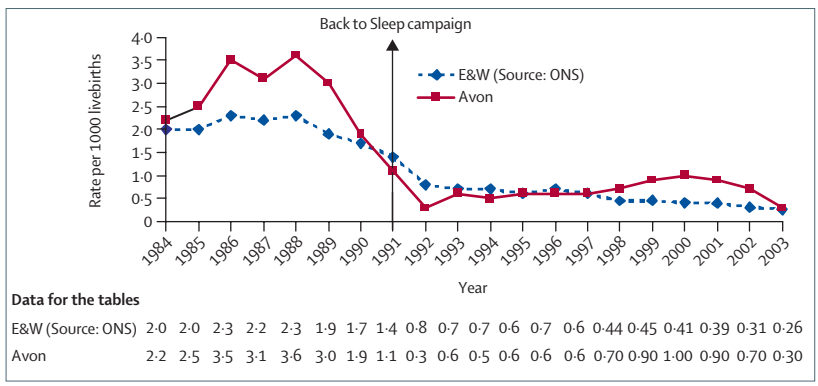
registered deaths in Avon showed no further deaths meeting the inclusion criteria. Thus, ascertainment was close to 100%. The median delay from an infant being found dead to a member of the study team contacting the family was less than 4 h, and families of 319 of the 369 deaths (86%) were contacted within 24 h of the death. Parents were interviewed in 348 cases (94·3%), and 331 homes were visited to review the scene and circumstances of death, including 274 (91·3%) of those eventually categorised as SIDS.

All deaths had a postmortem, and 300 (81·3%) were classified as SIDS at the review meeting. The remaining 69 were judged to have been fully explained, most commonly as a consequence of previously unrecognised infection, accidental or non-accidental injury, congenital malformations, or metabolic disorders. Investigation of the circumstances of death showed direct evidence of overlying or suffocation while bed-sharing in three unexpected deaths (one before and two after the Back to Sleep campaign), which were therefore not categorised as SIDS.

In the 1980s in Avon, 25-40 infants died of SIDS each year. This figure fell by more than 75% after the 1991 Back to Sleep campaign. Figure 1 compares the SIDS rate in Avon over the past 20 years with the SIDS rate in England and Wales. In Avon, a campaign led by local healthcare professionals in 1989–1990 was followed by a sharp fall in SIDS rates about a year before the national fall in rates that followed the Back to Sleep campaign in 1991.[17]

The national SIDS rate peaked with nearly 1600 deaths in 1988. These deaths were halved by the early 1990s, and have now fallen to fewer than 300 a year in England and Wales,[5] although we do not know how much of the recent reduction has been an effect of changes in certification practice.[11] In Avon, where there has been no change in diagnostic criteria, SIDS rates are slightly higher than the national rate.

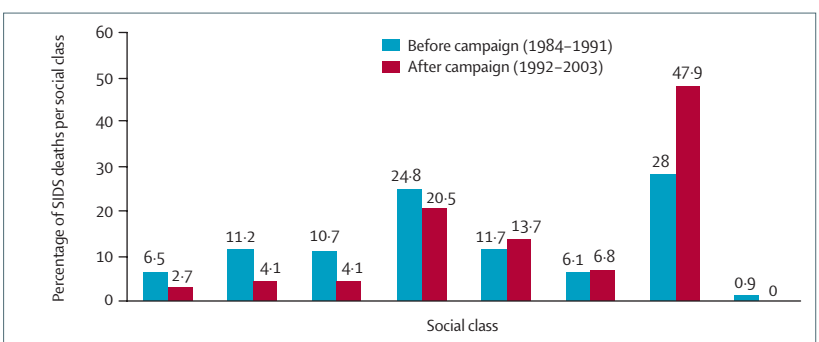
Figure 2 compares the social class of parents of children who died of SIDS before (1984–1991) and after (1992–2003) the Back to Sleep campaign. In the CESDI controls in the mid-1990s, the proportion of families with no waged income was 18%, and nationally unemployment had been falling since the mid-1980s. In the SIDS families, however, we see the opposite trend. Before the campaign, 28% of SIDS families had no waged income, but after the campaign, this proportion rose to 48%. Table 1 shows the socioeconomic status of SIDS families over the four consecutive 5-year intervals.



Data for the tables

E&W (Source: ONS)	2·0	2·0	2·3	2·2	2·3	1·9	1·7	1·4	0·8	0·7	0·7	0·6	0·7	0·6	0·44	0·45	0·41	0·39	0·31	0·26
Avon	2·2	2·5	3·5	3·1	3·6	3·0	1·9	1·1	0·3	0·6	0·5	0·6	0·6	0·6	0·70	0·90	1·00	0·90	0·70	0·30

Figure 1: **SIDS rates in Avon, compared with England and Wales, during 1984–2003**



Numbers

Social class	I	II	IIIn	IIIm	IV	V	Unemployed	Student or armed forces
Before (n=214)	14	24	23	53	25	13	60	2
After (n=73)	2	3	3	15	10	5	35	0

Figure 2: **Relation between social class of parents and SIDS deaths in Avon**

	1984–1988		1989–1993		1994–1998		1999–2003		p value for dichotomous differences	p value for trends in 5-year periods	CESDI controls	
	n/N	% (95% CI)	n/N	% (95% CI)	n/N	% (95% CI)	n/N	% (95% CI)			n/N	% (95% CI)
Socioeconomic marker												
Social class IV, V, and unemployed	72/153	47 (39–55)	33/73	45 (34–57)	18/27	67 (48–81)	25/34	74 (57–85)	0·008	0·003	223/1296	17 (15–19)
10% most deprived areas	34/146	23 (17–31)	23/69	33 (23–45)	9/30	30 (17–48)	16/33	48 (33–65)	0·03	0·006	..	..
Single mothers	24/152	15 (11–22)	12/74	16 (10–26)	15/30	50 (33–67)	14/35	40 (26–56)	<0·0001	<0·0001	69/1300	5 (4–7)
Maternal age <20 years*	11/154	7 (4–12)	10/73	14 (8–23)	6/29	21 (10–38)	5/32	16 (7–32)	0·1	0·03	84/1300	6 (5–8)
Maternal smoking during pregnancy	85/148	57 (49–65)	43/72	60 (48–70)	23/29	79 (62–90)	31/36	86 (71–94)	0·003	0·0004	348/1299	27 (24–29)

* Lowest quintile was chosen as cut-off.

Table 1: **Socioeconomic markers of SIDS families: trends in Avon over 20 years**

	1984–1988		1989–1993		1994–1998		1999–2003		p value for dichotomous differences	p value for trends in 5-year periods	CESDI controls	
	n/N	% (95% CI)	n/N	% (95% CI)	n/N	% (95% CI)	n/N	% (95% CI)			n/N	% (95% CI)
Sleeping position before death												
Put down on back	2/121	2 (0·5–6)	8/71	11 (6–21)	17/26	65 (46–81)	20/33	61 (44–75)	<0·0001	<0·0001	895/1295	69 (67–72)
Put down on side	11/121	9 (5–16)	14/71	20 (12–30)	3/26	12 (4–29)	5/33	15 (7–31)	0·2	0·3	361/1295	28 (26–30)
Put down on front	108/121	89 (82–94)	49/71	69 (58–79)	6/26	23 (11–42)	8/33	24 (13–41)	<0·0001	<0·0001	39/1295	3 (2–4)
Co-sleeping in parental bed	16/147	11 (7–17)	18/74	24 (16–35)	8/28	29 (15–47)	14/36	39 (25–55)	<0·0001	<0·0001	189/1299	15 (13–17)
Co-sleeping on a sofa	1/147	1 (0–4)	1/74	1 (0–7)	5/28	18 (8–36)	4/36	11 (4–25)	<0·0001	<0·0001	6/1299	0·5 (0·2–1)

Table 2: **Sleeping position before death of SIDS infants: trends in Avon over 20 years**

	1984–1988		1989–1993		1994–1998		1999–2003		p value for dichotomous differences	p value for trends in 5-year periods	CESDI controls	
	n/N	% (95% CI)	n/N	% (95% CI)	n/N	% (95% CI)	n/N	% (95% CI)			n/N	% (95% CI)
Characteristics												
Proportion of males	83/158	53 (45–60)	52/76	68 (57–78)	14/30	47 (30–64)	20/36	56 (40–70)	0·09	0·78	672/1300	52 (49–54)
Pre-term (<37 weeks)*	19/155	12 (8–18)	17/74	23 (15–34)	11/30	37 (22–54)	12/35	34 (21–51)	0·001	0·0001	70/1288	5 (4–7)
Low birthweight (<2500g)	21/155	14 (9–20)	13/73	18 (11–28)	10/29	35 (20–53)	6/32	19 (9–35)	0·06	0·07	66/1292	5 (4–6)
Multiple births	3/155	2 (1–6)	4/74	5 (2–13)	2/30	7 (2–21)	3/36	8 (3–22)	0·23	0·04	12/1300	1 (0·5–2)
Larger families (four or more children)†	22/154	14 (10–21)	9/74	12 (7–22)	6/30	20 (10–37)	13/36	36 (22–52)	0·01	0·005	100/1300	8 (6–9)
First-time mother	27/154	18 (12–24)	16/74	22 (14–32)	13/30	43 (27–61)	12/36	33 (20–50)	0·008	0·003	558/1300	43 (40–46)
Attempted to breastfeed	77/153	50 (42–58)	34/72	47 (36–59)	12/30	40 (25–58)	9/35	26 (14–42)	0·06	0·01	774/1298	60 (57–62)

*Defined as infants born before 37 weeks was completed; †Cut-off chosen as approximate lowest quintile.

Table 3: **Characteristics of SIDS infants and families: trends in Avon over 20 years**

Most of these markers of socioeconomic deprivation were seen at a higher frequency in SIDS families in Avon in the mid-1980s than they were in CESDI controls. All markers have become increasingly prevalent in SIDS families over the 20-year period; 75% are now classified as being in socioeconomic class IV, V, or unemployed, 86% of the mothers smoke, 40% are now single, 16% are younger than 20 years, and 48% of SIDS infants live in the 10% most deprived postcode areas.

Table 2 shows the change in practices of caring for sleeping infants over the past 20 years. In the 1980s, most infants who died of SIDS had been put to sleep in the prone position, as were most infants in the general population.[14,18] Over the past two decades, infants' sleeping position has changed greatly in Avon; the proportion of SIDS infants who had been placed prone to sleep has fallen from 89% to 24%.

Notably, in CESDI controls, a study done after the fall in SIDS rate showed that only 3% were placed prone. Clearly the Back to Sleep campaign has had a major effect on how parents choose their infants' sleeping position. The most common sleeping position for both SIDS infants and controls since 1991 was supine. The side position has also become more common, in particular with pre-term SIDS infants, 35% (8/23) being put to sleep in this position over the past 10 years compared with 7% (3/43) amongst SIDS term infants (p=0·02).

The increase in the prevalence of SIDS deaths when an infant slept with a parent rose from 12% in the 1980s to almost 50% in 1999–2003. Yet the actual number of SIDS deaths in the parental bed has halved (figure 3) from a median of four [IQR 3–5] deaths a year during 1984–91, to two [1·25–2·75] in 1992–2003 (p=0·01). This fall in SIDS deaths while bed-sharing, although significant, is smaller than the reduction in deaths in the cot, which could partly be due to differences in sleeping position between cot-sleeping and bedsharing infants. Before 1991, 91% of SIDS infants who died in a cot, but only 55% of the bedsharing SIDS infants were placed prone, whereas 37% of the bed-sharers were placed on the side. A reduction in sleeping prone would thus be

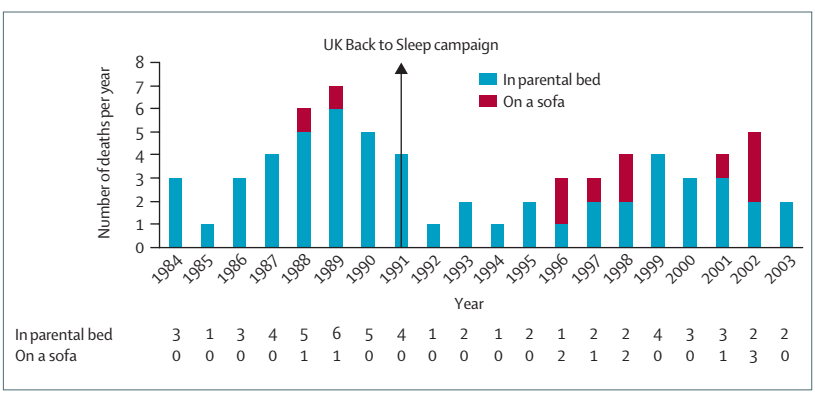


Figure 3: **Co-sleeping SIDS deaths in Avon during 1984-2003**

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expected to lead to a smaller fall in deaths in infants who bed-share compared with those who sleep in cots.

Although the number of deaths in the parental bed has fallen, the number of co-sleeping deaths on a sofa has worryingly risen in recent years.

The age at death of SIDS infants sleeping on their own has stayed about the same over the past 20 years. The median age of death of these infants was similar before (85 days [IQR 55-129]) and after (81 days [53–136]) the 1991 campaign, with few deaths in the first month (7%) or in those older than 8 months (6%). However, the median age of infants dying from SIDS while bed-sharing has significantly fallen from 88 days (44–127) before the end of 1991, to 54 days (33-84) after (p=0·007). The reason for this change is unclear.

SIDS has remained more common in males throughout the 20 years of the study (table 3). Prematurity, multiple births, and larger families have always been features of SIDS infants but these features are now much more prominent. First-born infants have previously been seen to be at lower risk of SIDS, but now, surprisingly, form the largest single group, whereas the proportion of SIDS mothers who attempted to breastfeed has halved. Stratifying for socioeconomic status, the growing linear trend in larger families was no longer significant, the increase in deaths in first-born infants (p=0·01) and decrease in breastfeeding (p=0·045) was only significant in deprived families, and increasing trend in pre-term infants was significant across social strata (social class I, II, IIIn/m: p=0·007, social class IV, V, never employed: p=0·01).

Discussion

The Back to Sleep campaign in the UK was successful in getting its primary message across; many parents have stopped putting their babies into the prone sleeping position and the number of SIDS deaths, especially those in a cot, have fallen greatly. Initially the side sleeping position was recommended as a safe alternative to prone but this advice changed in the mid-1990s when research[19] showed that the side position was unstable because of small infants rolling into the prone position.

Many midwives and neonatal nurses still prefer to put infants on their side rather than their back and continue to advise this position at the time of discharge from hospital because of a perceived risk of aspiration of vomit in the supine position,[20] despite an absence of forensic, pathological, or epidemiological evidence to substantiate these fears.[21]

The change in sleeping position has not just led to a major fall in the number of SIDS deaths; the epidemiology of SIDS has changed significantly.

Our data clearly show that SIDS is now largely confined to deprived families and almost half occur during co-sleeping. The rather alarming rise in prevalence of co-sleeping in recent SIDS case-control studies[6–9] has led some to recommend against bed-sharing,[9,22] and some countries have already adopted this stance.

However, our data indicate that this apparent rise in prevalence is more due to the effectiveness of campaigns in reducing SIDS deaths in infants sleeping alone (where deaths have fallen to a sixth of previous numbers) than an increase in deaths when bed-sharing. Indeed, the number of SIDS deaths in the parental bed in Avon has halved since the Back to Sleep campaign. More worrying is the rise in both prevalence and number of SIDS infants with a parent on a sofa. Whatever the contribution of unrecognised overlying in such deaths, we should continue to strongly recommend against parents co-sleeping in such an inappropriate environment.[23]

The change in socioeconomic status has led to some expected changes in the characteristics of SIDS families; an increase in single mothers, younger mothers, mothers who smoke, and lower birthweight infants. However, the prevalence of maternal smoking during pregnancy in SIDS mothers (80–90%) is twice that expected in control mothers with similarly deprived socioeconomic backgrounds,[13] lending support to the hypothesis that exposing infants to tobacco smoke is part of a causal mechanism. The prevalence of pre-term infants in those dying of SIDS has now tripled; over a third of SIDS infants are now pre-term compared with a population prevalence of 5%. This might partly be explained by the continued practice of using the side position for pre-term infants in maternity units.[21]

Some changes however have occurred with no obvious explanation. The age of bed-sharing SIDS infants has significantly fallen, the prevalence of mothers attempting to breastfeed has halved despite the increase in the prevalence of co-sleeping, and in terms of birth order, first-born SIDS infants are now the most common. The lower age of SIDS during bed-sharing might suggest that these vulnerable infants are being inadvertently lain over, but this does not hold up to closer scrutiny. The prevalence of bed-sharing in England is at its highest in the first month of life when the infant is most vulnerable,[24] yet the peak age of death in bed-sharing infants is a month later than this. Although overlaying might account for some of these deaths, there are likely to be other, as yet unidentified, factors at work.

The pathological basis of SIDS needs to be re-assessed, not just for consistent diagnosis but also to explore potential causes. Since the late 1990s, pathologists in the UK have been reluctant to diagnose SIDS when the death occurred while the infant was bed-sharing in an adult bed or when parents had been known to use illegal drugs.[11] This reluctance could explain the discrepancy between the national SIDS rate and that in Avon since 1997.

There are pathological clues as to why SIDS occurs but these have previously been thought to be too general for diagnostic purposes.[25] Careful gathering of clinical and pathological data might allow for detailed correlations

between important findings. Recognition of the changes in the epidemiology of SIDS since the Back to Sleep campaign should trigger careful re-analysis of the link between clinical and pathological findings.

Most SIDS infants are now found supine, most come from poor families, and many are bed-sharing. To understand the syndrome, we need to compare families who live in similarly deprived circumstances and infants who sleep in particular environments. The recognition of changing epidemiology could allow for appropriate comparisons to be made in future studies.

Data on death certification can vary in ascertainment, standards of investigation, and the definition of terms used. This study is potentially vulnerable to changes in the emphasis given to specific data collected at the death scene. However, there were surprisingly few omissions in this longitudinal data collection with near-complete ascertainment, standardised protocols, uniform definitions, and precise classifications used in the study.

Kennedy[3] and other researchers[10] emphasise the importance of a thorough investigation, including a multiprofessional review process in the identification of the causes of unexpected deaths in infancy, and the CESDI study showed that such a process was achievable in a well-funded large-scale 3-year research study.

Recent reports[26,27] have suggested that for many centres, such thorough investigations are unlikely to be maintained. Our study shows that, with close collaboration of all relevant agencies, such standards can be reached and maintained in a large population over the long term.

Contributors

P J Fleming and P J Berry created the original study design. P S Blair has worked as study statistician since 1992, and has contributed to the study design. P Sidebotham joined the group during data collection, and with P J Fleming, obtained clinical data. P J Berry and M Evans contributed post-mortem data and their interpretation. All authors helped manage data acquisition, were involved in the interpretation of P S Blair's analyses, and contributed to the drafting and revision of this manuscript.

Conflict of interest statement

We declare that we have no conflict of interest.

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