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Title

Unintentional asphyxia, SIDS, and medically-explained deaths: a descriptive study of outcomes of Child Death Review (CDR) investigations following sudden unexpected death in infancy.

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Abstract

Background

A comprehensive Child Death Review (CDR) program was introduced in England and Wales in 2008 but as yet data have only been analysed at a local level, limiting the learning from deaths. The aim of this study is to describe the profile of causes and risk factors for Sudden Unexpected Death in Infancy (SUDI) as determined by the new CDR program.

Methods

This was a descriptive outcome study using data from Child Death Overview Panel (CDOP) Form C for SUDI cases dying during 2010-2 in the West Midlands region of England. The main outcome measures were: cause of death, risk factors and potential preventability of death, and determination of deaths probably due to unintentional asphyxia.

Results

Data were obtained for 65/70 (93%) SUDI cases. 20/65 (31%) deaths were initially categorised as due to medical causes; 21/65 (32%) as SIDS, and 24/65 (37%) as undetermined. Reanalysis suggested that 2/21 SIDS and 7/24 undetermined deaths were probably due to unintentional asphyxia, with 6 of these involving co-sleeping and excessive parental alcohol consumption. Deaths classified as 'undetermined' had significantly higher total family and environmental risk factor scores (mean 2.6, 95% CI 2.0– 3.3) compared to those classified as SIDS (mean 1.6, 95% CI 1.2-1.9), or medical causes for death (mean 1.1, 95% CI 0.8-1.3). 9/20 (47%) of medical deaths, 19/21 (90%) SIDS and 23/24 (96%) undetermined deaths were considered to be potentially preventable. There were inadequacies in medical provision identified in 5/20 (25%) of medically explained deaths.

Conclusions

The CDR program results in detailed information about risk factors for SUDI cases but failed to recognise deaths probably due to unintentional asphyxia. The misclassification of probable unintentional asphyxial deaths and SIDS as 'undetermined deaths' is likely to limit learning from these deaths and inhibit prevention strategies. Many SUDI occurred in families with mental illness, substance misuse and chaotic lifestyles and most in unsafe sleep-environments. This knowledge could be used to better target safe sleep advice for vulnerable families and prevent SUDI in the future.

Key Words

Sudden Unexpected Death in Infancy (SUDI)

Sudden Infant Death Syndrome (SIDS)

Child Death Review (CDR)

Unintentional Asphyxia

Risk factors

Key points

The CDR program provides valuable information on the profile of causes and risk factors for SUDI but is currently not recognising deaths from unintentional asphyxia and often not classifying unexplained infant deaths as SIDS.

Most SUDI still occur in hazardous sleep environments despite public health campaigns.

Poor parenting, particularly the combination of excess parental alcohol consumption and co-sleeping, was a factor in many unexplained SUDI deaths.

Research is needed to help target safe-sleep information better at high risk families.

Difficulties with health care service provision may have contributed to some medically explained deaths.

BACKGROUND

Since 2008, all child deaths in England and Wales are subject to local child death review (CDR) with the aim of improving the welfare and safety of all children in the locality [1]. As yet data from this process have only been analysed at a local level limiting any wider learning. As part of a broader evaluation of the multi-agency investigation of Sudden Unexpected Death in Infancy (SUDI) we analysed CDR data on all SUDI cases in the West Midlands region of England from 2010-12 with the aim of improving our understanding of causes and risk factors for deaths to help prevent future deaths.

All unexpected child deaths, including SUDI cases, have mandatory detailed multi-agency investigation by police, health and social services aiming to identify, as far as possible, the complete cause of death including any relevant risk factors. A key element of this investigation is a joint home visit by specialist police and paediatrician to examine the scene of death, and a final case discussion when the cause of death is determined based on all available evidence. All information is then anonymised and reviewed by local multi-agency Child Death Overview Panels (CDOP); cases are discussed and a standard template (the CDOP Form C) is completed for each child, summarising the case and detailing cause and risk factors for death. These risk factors include those intrinsic to the child, in the family or environment, parenting capacity, and service provision. Risk factors can be marked on the Form C as yes/no, graded 0-3 for relevance or described in free text. Panel members also determine whether the death is considered preventable; this is defined in the CDR statutory guidance as 'those in which modifiable factors may have contributed to the death. These are factors defined as those, where, if actions could be taken through national or local interventions, the risk of future child deaths could be reduced.' [1]

SUDI is defined as 'the death of an infant that was not anticipated as a significant possibility 24 hours before the death, or where there was a similarly unexpected collapse leading to the death'[2]. SUDI cases may have a full cause for the death determined but most remain unexplained and are

labelled as either undetermined or Sudden Infant Death Syndrome (SIDS)[3]. Risk factors for SIDS are well known including parental smoking [4], hazardous sleeping environments[5] and prone sleep position [6]. Some SUDI are caused by unintentional asphyxia such as overlaying by a parent; these deaths are difficult to determine as SIDS deaths and those from unintentional asphyxia have many features in common [7]. Differentiation between SIDS and unintentional asphyxia relies on parental accounts and scene examinations because post-mortem examination findings are often insignificant [8] and not diagnostic [9].

We undertook a descriptive study of CDR outcomes for SUDI cases based in the West Midlands; this area has an infant mortality rate of 5.3 per 1000 live births [10] which is one of the highest in England.

The research question was: What is the profile of causes and risk factors for SUDI in one region of the UK?

METHODS

We obtained the dates of birth and death of all SUDI cases in the study region aged between one week and one year, dying between 1 September 2010 and 31 August 2012, from the pathology departments at Birmingham Women's Hospital and Birmingham Children's Hospital. These two centers conduct all infant post-mortem examinations for the locality. The study region consisted of the counties of Warwickshire, West Midlands, Worcestershire, Staffordshire, Shropshire and Herefordshire. We contacted the Chairs of all ten local CDOPs and asked for copies of the Form C for all relevant SUDI cases. These forms had been completed routinely during CDOP meetings and were subsequently provided to us in an anonymised format.

There was considerable variation in how Form Cs were completed by individual CDOPs leading to difficulties comparing forms. The grading of risk factors using the 0-3 scale was inconsistent; risk

factors were frequently only mentioned in the narratives but the relevance of these was not always recognised, leading to disparate conclusions on the potential preventability of deaths. Therefore, using the data available on each Form C, JG and CE, who are experienced CDOP members, independently completed the risk factor yes/no and 0-3 grade fields and considered the potential preventability of each death. We then compared results and discussed and resolved any differences. To assist coding, we created a reference list of risk factors for SUDI based on the Avon Clinico-Pathological Classification [11]; these risk factors are shown in table 1.

There is no published guidance on determining risk factors for parenting capacity or service provision. We considered parenting capacity as a risk if poor parenting had contributed in any way to the death, even if an isolated event; this included co-sleeping deaths with parents consuming more than two units of alcohol but excluded other unsafe sleep deaths without substance involvement. Risk factors for service provision included failings in medical care, lack of provision of services or access to them. We decided that parents not engaging with services, for whatever reason, counted as parenting issues rather than service provision issues, although we recognised that in some cases lack of engagement may reflect lack of provision of services appropriate to the needs of vulnerable families.

We entered the following data items for each case into a SPSS database: age at death, narrative description of cause of death, presence of significant risk factors at level 2 or greater, potential preventability of death, and documented provision of safe sleep information. We created a total family and environmental risk factor score for each case. We gave a score of 1 for each of: any unsafe sleeping environment (such as the use of soft bedding or co-sleeping); parental alcohol consumption of greater than two units or illicit drug use the night before death; parental mental illness at the time of death; housing issues; domestic violence; and maternal smoking. The maximum score was 6; this score was intended as a descriptive tool detailing the circumstances of deaths rather than as an assessment of effectiveness of determining risk factors.

We considered the possibility of unintentional asphyxia for all unexplained deaths; this was considered separately from the total family and environmental risk factor score. Asphyxia was considered probable if both the autopsy findings and the circumstances of death supported this, or if the infant was found under a parent or at the bottom of the parents' bed under bedding, or if there were other significant suffocation hazards. Infants found face down were not considered to have asphyxiated in the absence of other factors as this is a common SIDS finding, possibly representing a failure of arousal mechanisms [12]. This method may both overestimate or underestimate unintentional asphyxia, recognising that overlaying may occur after the infant has died of another cause, or that a parent may cause asphyxia through overlaying, but subsequently move so the infant is found with no apparent airway obstruction.

We used 3-way chi-squared test for determining significant associations between risk factors and classification of death, with $p < 0.05$ considered statistically significant. Since 'acute illness' was both a classification of death and a potential risk factor for unexplained deaths a 2-way chi-squared test was performed for acute illness comparing SIDS with deaths classified as undetermined.

Ethical approval was granted from the University of Warwick Biomedical and Scientific Research Ethics Committee.

RESULTS

There were 70 SUDI cases having post-mortem examinations at the two pathology departments during the two year study period with the Form C available for 65 cases (93%). Due to the anonymisation of the forms we could not ascertain which cases were missing or the reasons for non-availability. Form Cs had complete information (although not necessarily correctly formatted) in 53/65 (82%) cases. In 10/12 cases missing information related to a single item. Two cases, from different CDOPs, were missing several items of information in one of which it was not possible to determine the preventability of death.

In 52/65 (80%) cases there was complete agreement initially between CE and JG on reanalysis of Form Cs. In 30/65 (46%) cases reanalysis of Form Cs only involved standardising the format of information but in 35/65 (54%) cases reanalysis included reinterpreting the information according to our reference list, leading to reclassification of risk factors and potential preventability of death.

The median age at death was 2.3 months for all deaths, 3.1 months for medical deaths, 2.0 months for SIDS, and 2.1 months for undetermined deaths. 48/65 (74%) deaths were of males.

Causes of death

Causes of death are shown in table 2.

At initial CDOP classification most deaths (69%) remained unexplained. 12/20 medical deaths were from infection and 6/20 from cardiac disease.

Deaths due to unintentional asphyxia

No deaths were identified on Form Cs by CDOPs as due to unintentional asphyxia; however after reanalysis 2/21 SIDS and 7/24 undetermined deaths were considered probably asphyxial. In two cases there were significant post-mortem examination findings consistent with asphyxia. Five infants were found at the bottom of their parents' beds, face down and entirely covered with bedding, two infants were found directly under parents. In six of the nine cases, parents were probably intoxicated with alcohol, all six deaths involved co-sleeping and one infant was found under a parent. The remaining 17 undetermined deaths met criteria for a diagnosis of SIDS [3] and were reclassified as such.

Risk Factors

The distribution of risk factors in relation to the CDOP classification of cause of death is shown in figure 1. Risk factors and potential preventability of death are shown in table 3.

Risk Factors Intrinsic to the Child

The acute illness directly causing death was the only intrinsic risk factor in 9/20 medical deaths.

There were no significant differences between classification of death and previous prematurity or congenital anomalies; this probably reflects that infants with congenital anomalies or previous prematurity have increased vulnerability so are more likely than other infants to die of any cause.

Risk Factors Extrinsic to the Child (Family and Environment)

The total number of family and environmental risk factors and cause of death are shown in figure 2.

Those deaths classified by CDOPs as undetermined had significantly higher total family and environmental risk factor scores with a mean of 2.6 (95% CI 2.0– 3.3) compared to 1.6 (95% CI 1.2– 1.9) for SIDS and 1.1 (95% CI 0.8–1.3) for medical causes. SIDS and undetermined deaths were significantly more likely to be in an unsafe sleep environment than medically-explained deaths and to occur in families with maternal smoking in pregnancy or postnatally ($p=0.006$); however there was no significant difference in co-sleeping between SIDS, undetermined deaths and medically-explained deaths. The parents of undetermined cases were significantly more likely than those of SIDS or medically-explained deaths to have consumed more than two units of alcohol or taken illicit drugs the night before death ($p=0.004$), or to have mental health problems ($p=0.009$). The combination of alcohol consumption and co-sleeping occurred in 2/8 co-sleeping SIDS and 6/14 co-sleeping undetermined deaths. In three unexplained deaths co-sleeping occurred without other environmental risk factors; two cases were of premature infants who had barely reached term; only one infant died co-sleeping in the absence of any other risk factors.

Only three unexplained deaths had no risk factors in the family and environment; however all of these infants were intrinsically vulnerable due to previous prematurity, multiple births or congenital abnormalities.

Risk Factors for Parenting Capacity

Risk factors for parenting capacity were identified by local CDOPs in 9 cases and by the research team in an additional 12 cases; the risk factors identified by both groups were similar. Risk factors for parenting capacity were significantly associated with undetermined deaths ($p=0.016$); mainly due to co-sleeping with alcohol consumption. Poor parenting in some families had been a concern to professionals prior to the death. Parenting risk factors for medical deaths involved young mothers with chaotic lifestyles failing to recognise illness in their infants or not engaging with services. There were no deaths in this series for which the CDOP had identified child maltreatment or intentional asphyxiation as a cause.

Risk Factors for Service Provision

There were five medically-explained deaths in which issues with service provision potentially contributed. In two cases infants missed immunisations and died of vaccine preventable diseases; primary care services had not engaged with parents about this. In three cases there was concern that primary care or community health teams had not managed cases appropriately.

Potential Preventability of deaths

Potential preventability of death was significantly associated with SIDS and undetermined deaths ($p=0.001$) although nearly half of medical deaths were also potentially preventable.

Provision of safe sleep information

In 22/45 unexplained deaths it was clearly documented that parents had been given safe sleep information but in two of these language difficulties may have limited its value. In 5/23 cases without documented information provision families had not engaged with services so may not have received safe sleep advice.

DISCUSSION

Very few SIDS or undetermined infant deaths occurred in the absence of environmental risk factors, and these few deaths concerned infants who were inherently vulnerable due to factors such as

prematurity. One-fifth of otherwise unexplained SUDI were probably caused by unintentional asphyxia; in these cases commonly parents co-slept with infants after excessive alcohol consumption. Those deaths probably caused by unintentional asphyxia, along with a majority of those that remained unexplained may have been preventable had parental care been different, particularly if safe sleeping advice had been consistently followed, including avoiding co-sleeping if parents have consumed alcohol, or are smokers, or the infant is premature. A minority of medically-explained deaths may have been preventable had different actions been taken by health care providers.

This is the first study to combine data from several local CDOPs, enabling a large set of similar deaths to be studied; although CDOPs were established in 2008, as yet no national outcomes have been published. Although the results are purely from the West Midlands region of England, the findings should be generalizable as the profile of risk factors and causes of death is similar to those found in other UK or international studies [13] [14]. Detailed information on risk factors was available for all SUDI cases regardless of final cause of death as all SUDI cases had complete multi-agency investigations. A limitation of the study is that the quality of the data was entirely dependent on individual CDOPs; there were significant disparities of the detail recorded on Form Cs. There is the potential that some information on risk factors collected for medically-explained deaths was subsequently not recorded on Form Cs, as CDOPs may not have considered this relevant given the medical cause of death; however this seems unlikely as most Form Cs, regardless of cause of death, were very detailed. Our interpretation that lack of engagement by parents with services was a parenting risk factor rather than that of service provision may have resulted in an underestimation of the service provision concerns as these were only identified in medically-explained deaths. Other research has found service provision and in particular lack of recognition of illness to be relevant in all types of SUDI [2]. It could be that the lack of engagement may reflect services that are poorly suited to the needs of vulnerable families and thus be a service provision issue rather than poor parenting as such. However, in some cases service providers had documented repeated attempts to

engage with parents but in many others we had little information to inform our judgement. Another criticism of our analysis could be that we were unduly harsh in our consideration of risk factors for parenting capacity. However, our interpretation of the combination of alcohol and co-sleeping as a parenting risk concurs with a study of CDR panel members from the USA where 89% of respondents agreed that neglect played a role in such deaths [15].

This is the first study to evaluate the English multi-agency SUDI investigations in routine practice.

Only one other study has used a multi-agency approach to investigating SUDI but the clinicians were assisted by dedicated research teams [16]; despite this there were similar proportions of medically-explained deaths, rates of maternal smoking and hazardous sleeping environments[13]. Other studies of outcomes of SUDI investigations found that missing information from death scenes or concerning parental alcohol and smoking habits were commonplace[14, 17, 18]; in comparison only minimal information was missing in this study. This shows not only the quality of the CDOP data but also of the robustness of the multi-agency investigative process.

This study highlights the difficulties in correctly classifying causes of infant deaths; there were several deaths probably due to unintentional asphyxia but not labelled as such. This reflects standard UK practice as in 2014 only 6 infant deaths nationally were registered with ICD10 code W75 (accidental suffocation and strangulation in bed) [19]. There is a wide variation internationally in the use of ICD10 code W75 for infant sleep related deaths, ranging from 1.1% in Germany to 31.7% in New Zealand with England and Wales at 3.8%[20]; some of this variation may be due to differences in CDR with countries such as New Zealand having a robust CDR process[21]. Additionally, in our study only around half of unexplained deaths were categorised as SIDS with the remainder, especially those with more risk factors, labelled as undetermined. All these deaths, having had the requisite investigations, could be correctly classified as SIDS [3] although this is not current UK paediatric pathologists' practice [22]. These difficulties with classifying the cause of death may relate to weaknesses in the multi-agency investigation of SUDI, which concludes with a case discussion to

determine the cause of death prior to review by CDOP. In this study the conclusions of case discussions were nearly always identical to the pathologists' and did not take fully into account findings from death scene examinations. This may relate to the relative inexperience of many pediatricians conducting death scene examinations who may lack confidence in interpreting the findings. As SUDI is a rare event, many pediatricians manage cases very infrequently limiting their ability to build up expertise. A systematic review of SUDI investigation found that death scene examination is most effective when done by professionals with specialist training who perform these regularly [23]. We should therefore consider whether SUDI investigation should become a specialist pediatric service commissioned on a regional basis similar to the provision of pediatric post-mortem examinations. If the current trend continues in labelling more deaths as undetermined, combining SIDS and unintentional asphyxia deaths into the same category, this will impede further analysis of causes of death thus limiting possible learning and potential strategies to prevent future deaths.

This study has shown the utility of the new English CDR program in identifying risk factors for SUDI; this can then allow appropriate preventative strategies to be developed. This is particularly pertinent as the study clarified that most unexplained infant deaths are potentially preventable occurring in highly hazardous sleeping environments and in families with mental illness, drug or alcohol misuse and chaotic lifestyles. Clearly there are difficulties with health education messages either not reaching these families, parents possibly not understanding the information, or parents deciding not to follow safe-sleep advice [24]. Current practice in the region is that safe sleep information is shared with all families before and after birth by both midwives and health visitors, however this is usually limited to a brief discussion supported by written information [25]. When families declined to engage with health professionals it limited their opportunity to access safe sleep information.

This study raises two challenges: first, we need to find ways of improving the CDR program for SUDI cases, including better recognition of parenting risk factors and identification of unintentional asphyxial deaths; this may require a review of SUDI investigative provision to ensure clinicians are

adequately trained, experienced and resourced. If we do not acknowledge this issue we cannot consider preventative strategies. Secondly, we need to consider how best to share safe-sleeping advice so that we can then find better ways to support families in making wiser choices to allow their children to grow up healthily.

DECLARATIONS

List of abbreviations

CDOP Child death overview panel

CDR Child death review

SIDS Sudden infant death syndrome

SUDI Sudden unexpected death in infancy

Ethical approval

This study was approved by the University of Warwick Biomedical and Scientific Research

Committee, reference number 245-10-2012

Competing interests

JG had financial support from NIHR for the submitted work; all authors had no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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Authors contributions

The study was designed by JG, FG and PS. JG collected all data, conducted the analyses and wrote the initial report. CE and JG reanalysed Form Cs. FG and PS advised on study progress and data analysis. All authors commented on and approved the final version of the manuscript, have a copy of the manuscript and share responsibility for the results.

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Availability of data and materials

Data may be available on request from the first author.

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Table 1 Evidence base for risk factors for SUDI

| Category | Risk Factor | Reference |
|--|--|--|
| Intrinsic to the child | Acute illness (eg URTI /otitis media) with symptoms present at time of death but not significant as a cause of death | Gilbert et al. [26] |
| | Preterm birth before 37 weeks gestation | Blair et al. [13] |
| | Congenital anomaly not causing death | Leach et al. [27] |
| | Multiple birth | Carpenter et al. [28] |
| | Previous unexplained infant death | Bacon [29]Carpenter et al. [28] |
| | Small for gestational age | Leach et al. [27] |
| | Male infant | Leach et al. [27] |
| Extrinsic to the child -Family and Environment | Symptomatic depression in mother or primary carer at time of death | Mitchell et al. [30] |
| | Alcohol use by mother > 2 units in last 24 hours | Blair et al. [13], Carpenter et al. [31] |
| | Substance misuse by parent | Blair et al. [13]Carpenter et al. [31] |

| | | |
|--|---|---|
| | Smoking by mother in pregnancy or postnatally | Blair et al. [13] |
| | Poor housing or overcrowding | Leach et al. [27] Spencer, Logan [32] |
| | Domestic violence | Spencer, Logan [32] |
| | Co-sleeping | Blair et al. [13] Carpenter et al. [31] |
| | Sleeping on pillow or other soft surface eg adult duvet | Blair et al. [13] |
| | Sleeping prone or side sleeping | Carpenter et al. [28] |

Table 2 Classification of cause of death

| Cause of death | | Pathologist/Coroner classification | CDOP classification | Research team classification |
|------------------------|--------------|------------------------------------|---------------------|------------------------------|
| Medical Cause | | 20 (31%) | 20 (31%) | 20 (31%) |
| Unintentional asphyxia | | 0 (0%) | 0 (0%) | 9 (14%) |
| Unexplained, of which: | | 45 (69%) | 45 (69%) | 36(55%) |
| | SIDS | 19 (29%) | 21 (32%) | 36(55%) |
| | Undetermined | 26 (40%) | 24 (37%) | 0 (0%) |

Table 3 Risk factors and potential preventability of death

| | CDOP Classification | | | |
|-------------|------------------------|---------------|---------------------|----------------------|
| Risk Factor | Medical cause of death | SIDS (n=21**) | Undetermined (n=24) | Chi-Square (p-value) |

| | | | | |
|--|-----------------------|----------|----------|----------------|
| | (n=20*) | | | |
| Factors intrinsic to the child | | | | |
| Any intrinsic risk factor | Not Applicable *** | 9 (43%) | 15 (63%) | 1.348 (>0.25) |
| Acute illness | Not Applicable *** | 4(19%) | 9 (38%) | 1.605 (>0.25) |
| Prematurity | 8 (40%) | 5 (24%) | 3 (13%) | 4.400 (>0.25) |
| Congenital anomaly | 6 (30%) | 2 (10%) | 4 (17%) | 2.735 (>0.25) |
| Factors extrinsic to the child (family and environment) | | | | |
| Any unsafe sleep environment | 8 (40%) | 15 (71%) | 20 (83%) | 8.431 (0.015) |
| Co-sleeping with a parent | 5 (25%) | 8 (38%) | 14 (58%) | 4.672 (0.097) |
| Parental alcohol or illicit drug use | 2 (10%) | 3 (14%) | 12 (50%) | 10.981 (0.004) |
| Maternal smoking | 6 (30%) | 11 (52%) | 20 (83%) | 10.246 (0.006) |
| Current parental mental health issues | 2 (10%) | 0 (0%) | 8 (33%) | 9.432 (0.009) |
| Housing Issues | 4 (20%) | 5 (24%) | 6 (25%) | 0.94 (0.954) |
| Domestic violence | 4 (20%) | 1 (5%) | 4 (17%) | 2.673 (0.263) |
| Factors in parenting capacity | | | | |

| | | | | |
|--|------------|----------|----------|----------------|
| Parenting capacity | 3/20 (15%) | 5 (24%) | 13 (54%) | 8.276 (0.016) |
| Potential preventability of death | | | | |
| Death potentially preventable | 9 (47%) | 19 (90%) | 23 (96%) | 19.574 (0.001) |

*for 1 medical death lack of information meant that preventability of death could not be assessed

** for 1 SIDS case information on factors intrinsic to the child was missing

*** We excluded acute illness in the medically explained deaths as this was the actual cause of death rather than a risk factor as such.