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Garstang, Joanna Jane; Menka, Marivjena

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# BMJ Paediatrics Open

# Infant death from accidental suffocation and strangulation in bed in England and Wales: rare or unrecognised events?

Joanna Jane Garstang 💿 ,<sup>1,2</sup> Marivjena Menka 💿 <sup>1</sup>

# ABSTRACT

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<sup>1</sup>College of Medical and Dental Sciences, University of Birmingham, Birmingham, UK <sup>2</sup>Children and Family Services, Birmingham Community Healthcare NHS Trust, Aston, UK

### **Correspondence to**

Dr Joanna Jane Garstang; j. garstang@bham.ac.uk

Background Mandatory joint police and healthcare investigations of sudden unexpected death in infancy (SUDI) have been in place since 2008 in England. These include death scene examination with cause of death determined at multiprofessional case conference. Detailed evidence on sleep arrangements is available for most cases potentially leading to more being identified as due to accidental suffocation. SUDI remaining unexplained following investigation are classified as SIDS (sudden infant death syndrome) or unspecified deaths. Our objective was to determine whether detailed SUDI investigation has led to an increase in deaths classified as accidental suffocation or strangulation in bed (ASSB)? Methods We obtained official mortality data for England and Wales for infants dying aged 0-364 days for International Statistical Classification of Diseases and Related Health Problems, 10th revision codes R95 (SIDS), R96, R98, R99 (unspecified causes of mortality) and W75 (ASSB) for the years 2000-2019.

We calculated the mortality rate for ASSB, SIDS and unspecified causes based on total live births each year. Results Unexplained SUDI decreased from 353 in 2000 to 175 in 2019, with the mortality rate falling from 0.58 to 0.29 per 1000 live births. The total postneonatal mortality rate fell during this time from 1.9 to 0.9 per 1000 live births suggesting this is a genuine fall. SIDS accounted for 70% of unexplained SUDI in 2000 falling to 49% in 2020 with a corresponding increase in R99 unspecified deaths. Few deaths were recorded as ASSB (W75), ranging between 4 in 2010 and 24 in 2001. The rate for ASSB ranged from 0.6 to 4.0 per 100000 live births. **Conclusions** There is a shift away from SIDS (R95) towards unspecified causes of death (R96, R98, R99). Improved investigation of deaths has not led to increased numbers of death identified as due to ASSB. There needs to be clear guidelines on accurate classification of deaths from ASSB to facilitate learning from deaths and inform prevention efforts.

# **INTRODUCTION**

Sudden unexpected death in infancy (SUDI) is the sudden and unexpected death of an infant which would not have been reasonably expected to occur 24 hours previously and where no pre-existing medical cause of death is apparent.<sup>1</sup> There are around 350 such deaths in England each year, of which

# WHAT IS ALREADY KNOWN ON THIS TOPIC

- $\Rightarrow$  Sudden infant death syndrome has declined significantly since the 1990s and continues to fall.
- $\Rightarrow$  Since 2008, in England, all sudden infant deaths have detailed multiagency investigation.
- ⇒ Many sudden infant deaths occur in hazardous sleep circumstances involving cosleeping with parents who have consumed alcohol or drugs.

# WHAT THIS STUDY ADDS

- ⇒ Detailed multiagency investigation of sudden infant deaths has not led to an increased recognition of deaths from accidental suffocation or strangulation in bed (ASSB).
- ⇒ It is likely that deaths from ASSB are being missed as rates in England and Wales are much lower than other countries with detailed sudden infant death investigation.

# HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- $\Rightarrow$  There needs to be clear guidance for classifying cause of death for sudden infant deaths.
- ⇒ Recognition of ASSB deaths could help inform efforts to prevent sudden infant deaths, by empowering professionals to discuss risks and mechanisms for death with parents.

approximately half have a cause subsequently identified, for example, congenital malformation or infection, and half remain unexplained.<sup>2</sup> Unexplained deaths may be classified as sudden infant death syndrome (SIDS) although the term 'unascertained' is also used frequently when pathologists have been unable to establish a cause of death. SIDS is defined as the sudden unexpected death of an infant with the onset of the lethal episode occurring during sleep, which remains unexplained after thorough investigation. This includes a complete postmortem examination, review of circumstances of death and clinical history.<sup>3</sup>

The risk factors for SIDS are well known, many relate to the sleep environment as well as exposure to tobacco smoke antenatally and postnatally.<sup>4</sup> The highest risks relate to tobacco-exposed infants sharing sleep surfaces with adults who have consumed alcohol or drugs. A metaanalysis determined an adjusted OR of 151 (95% CI 50 to 448) for death of infants cosleeping in bed with parents who were tobacco smokers and had consumed alcohol or drugs in the previous 24 hours.<sup>5</sup> The comparison was infants room-sharing with non-smoking, non-drug or alcohol using parents but these control infants have a very low risk of SUDI potentially exaggerating the OR. In contrast, a pooled analysis of two case-control studies determined an OR of 18.3 (95% CI 7.7 to 43.5) for infants cosleeping on a sofa with an adult who had consumed more than two units of alcohol compared with infants sleeping alone.<sup>6</sup> Some of these deaths may be due to accidental suffocation. However, this is difficult to determine as postmortem examination for both SIDS and accidental suffocation have similar non-specific findings,<sup>7</sup> and there are no diagnostic findings.<sup>8</sup> The diagnosis of accidental suffocation relies on a careful history and death scene examination. There is no international consensus on the diagnosis of accidental suffocation in infants.

As SIDS rates have declined significantly since the 1990s, the proportion in highly hazardous sleep environments has increased.<sup>9</sup> UK pathologists prefer to classify deaths with sleep environment risk factors as unascertained rather than SIDS<sup>10</sup> and now nearly half of UK unexplained infant deaths are classified as 'unascertained'.<sup>11</sup> There is considerable international variation in the classification of cause of death following SUDI.<sup>12</sup> Reanalysis of cases originally determined as SIDS in New Zealand and New South Wales identified that up to 20% may have been due to accidental suffocation.<sup>13 14</sup>

In the UK, the determination of the cause of death following SUDI rests with coroners, death certificates are based on the coronial process. Since 2008, in England, this should be informed by a detailed multiagency investigation, including a joint home visit by police and healthcare professionals with death scene analysis. The process concludes with a multiprofessional case conference documenting all relevant factors and an opinion as to the cause of death.<sup>1</sup> A similar process exists in Wales, although there are no joint home visits and police visit scenes of death alone.<sup>15</sup> The National Child Mortality Database (NCMD) has collated information from reviews of all child deaths in England since April 2019. Joint home visits took place for 65% of SUDI between 2019 and 2021, 48% of unexplained deaths occurred in hazardous cosleeping environments involving parental drugs, alcohol, smoking, preterm or low birthweight infants.<sup>2</sup> Previous research has identified that coroners frequently rely on the conclusion of the postmortem examination alone and not the wider multiagency investigation,<sup>16</sup> and child death overview panels may disagree with pathologists on the cause of death.<sup>17</sup> The aim of this study is to identify if improvements in the investigation of SUDI and identification of hazardous sleep environments has resulted in any changes in the classification of causes of death.

The research question was: has detailed SUDI investigation led to an increase in infant deaths classified as accidental suffocation or strangulation in bed (ASSB)?

# **METHODS**

We searched official mortality statistics for data on deaths of infants aged from 0 to 364 days in the years 2000–2019. These data are based on death certificates registered in England and Wales with cause of death as determined by coroners. Underlying causes of death were coded according to International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10).<sup>18</sup> We included deaths certified due to the following ICD-10 codes: R95 SIDS, R96 other sudden death, cause unknown, R98 unattended death, R99 other ill-defined and unspecified causes of mortality and W75 accidental suffocation and strangulation in bed (ASSB). We have referred to these combined codes R95–98 and W75 as sleep-related SUDI.

We excluded codes W76–84 other accidental threats to breathing, as these may not have occurred in a sleep environment and W78 inhalation of gastric contents may represent an agonal process.

Data for the years 2013–2019 were obtained directly from the Office for National Statistics website using the 'Query Data' feature.<sup>19</sup> We obtained data for deaths for 2000–2012 directly from Office for National Statistics which supplied this from their archive.

We obtained live birth numbers, neonatal and the postneonatal mortality rate for all years directly from the Office for National Statistics website.

We calculated the total sleep-related SUDI, the proportions linked to each ICD-10 code and the mortality rate for ASSB for each year.

We did not involve bereaved families directly in this project although the findings have been discussed with them.

# RESULTS

The total number of sleep-related SUDI fell from 365 in 2000, to its lowest of 185 in 2019. Unexplained infant deaths (R95–99) decreased from 353 in 2000 to 175 in 2019. There were few deaths recorded in any year due to ASSB, the least was 4 in 2010 and the most was 24 in 2001.

The numbers of deaths for each year by ICD-10 code and infant mortality rates are shown in table 1. There were no deaths recorded under R98 for the entire period, so this code has been omitted. The fall in numbers of unexplained infant deaths is unlikely to be due to these deaths being classified under other ICD-10 codes as there has been an overall decline in total neonatal and postneonatal deaths over the same period. The decline in the number of sleep-related SUDI is illustrated in figure 1.

The proportion of sleep-related SUDI classified as R95 SIDS fell slightly from 68% in 2000 to 46% in 2019 with a corresponding increase in R99. SIDS accounted for 70%

Table 1	Number of sleep-related SUDI for each ICD-10 code and infant mortality rates 2000–2019							
	Number of deaths for ICD-10 codes % of total sleep-related SUDI						Neonatal	
Year	R95%	<b>R96</b> %	R99%	R95%-99%	W75%	<ul> <li>Total sleep-related SUDI (R95–99 and W75)</li> </ul>	mortality rate/1000 live births	Postneonatal mortality rate/1000 live births
2000	247	0	106	353	12	365	3.9	1.8
	67.7%	0.0%	29.0%	96.7%	3.3%			
2001	245	0	102	347	24	371	3.6	1.9
	66.0%	0.0%	27.5%	93.5%	6.5%			
2002	193	0	111	304	20	324	3.6	1.7
	59.6%	0.0%	34.3%	93.8%	6.2%			
2003	185	0	145	330	21	351	3.7	1.8
	52.7%	0.0%	41.3%	94.0%	6.0%			
2004	212	0	119	331	12	343	3.5	1.6
	61.8%	0.0%	34.7%	96.5%	3.5%			
2005	224	1	114	338	16	354	3.5	1.7
	63.1%	0.3%	32.1%	95.5%	4.5%			
2006	194	0	111	305	15	320	3.5	1.5
	60.6%	0.0%	34.7%	95.3%	4.7%			
2007	205	0	94	299	12	311	3.3	1.6
	65.9%	0.0%	30.2%	96.1%	3.9%			
2008	190	0	118	308	13	321	3.3	1.5
	59.2%	0.0%	36.8%	96.0%	4.0%			
2009	194	1	113	308	7	315	3.2	1.5
	61.6%	0.3%	35.9%	97.8%	2.2%			
2010	163	1	111	275	4	279	3	1.4
	58.4%	0.4%	39.8%	98.6%	1.4%			
2011	172	0	97	269	14	283	3	1.3
	60.8%	0.0%	34.3%	95.1%	4.9%			
2012	174	0	78	252	7	259	2.9	1.3
	67.2%	0.0%	30.1%	97.3%	2.7%			
2013	170	0	104	274	5	279	2.8	1.2
	60.9%	0.0%	37.3%	98.2%	1.8%			
2014	133	0	109	242	12	254	2.6	1.2
	52.4%	0.0%	42.9%	95.3%	4.7%			
2015	124	0	83	207	9	216	2.7	1.1
	57.4%	0.0%	38.4%	95.8%	4.2%			
2016	118	0	133	251	4	255	2.8	1.1
	46.3%	0.0%	52.2%	98.4%	1.6%			
2017	111	0	94	9	9	204	2.8	1.1
	51.9%	0.0%	43.9%	95.6%	4.4%			
2018	111	0	94	9	9	204	2.8	1
	51.9%	0.0%	43.9%	95.6%	95.6%			
2019	86	0	89	175	10	185	2.8	1
	46.5%	0.0%	48.1%	94.6%	5.4%			

R95=SIDS.

R96=other sudden death, cause unknown.

R99=other ill-defined and unspecified causes of mortality. W75=ASSB.

ASSB, accidental suffocation and strangulation in bed; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th revision; SIDS, sudden infant death syndrome; SUDI, sudden unexpected death in infancy.

of unexplained infant deaths in 2000 falling to 49% in 2020. The proportion of sleep-related SUDI classified as W75 ASSB fluctuated between 1.4% and 6.0% over time. This is shown in figure 2.

The total unexplained infant mortality rate for R95–99 combined fell from 0.58 per 1000 live births in 2000 to 0.29 in 2019. There was no increase in W75 deaths in this time, with W75 deaths ranging from 0.6

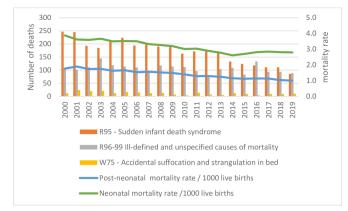


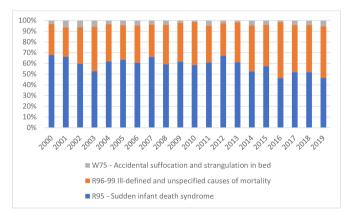
Figure 1 Decline in sleep-related SUDI and infant mortality rates 2000–2019. SUDI, sudden unexpected death in infancy.

per 100 000 live births in 2016 to 4.0 in 2001. This is shown in figure 3.

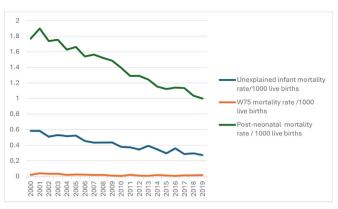
# DISCUSSION

Overall, sleep-related SUDI has fallen by over 40% from 365 to 185 deaths per year from 2000 to 2019, this is not just a diagnostic shift as evidenced by the accompanying decline in postneonatal mortality rate. The decrease in sleep-related SUDI is likely due to the ongoing safe-sleep campaigns and reduction in parental smoking.<sup>20</sup> The fall is largely in cases classified as SIDS, there were 247 SIDS cases in 2000 and 86 in 2019, an overall reduction of over 65%. The number of sleep-related SUDI classified as 'unascertained' has fluctuated over time ranging between 78 and 145 deaths per year. There has been no increase in the number of deaths classified as accidental suffocation and strangulation in bed (ASSB) despite statutory multiagency SUDI investigation.

This study included all sleep-related SUDI in England and Wales over a 20-year period, a total of 5793 cases. Postmortem examination has been mandatory for SUDI throughout this period, with all postmortems conducted by specialist paediatric pathologists required by law



**Figure 2** Proportion of sleep-related SUDI by ICD-10 codes 2000–2019. ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th revision; SUDI, sudden unexpected death in infancy.



**Figure 3** Unexplained infant mortality rate (R95–99), W75 rate and postneonatal mortality rate 2000–2019.

from 2008 although many had paediatric examinations before then.<sup>21</sup> Similarly, multiagency investigation has improved considerably since 2008, with 65% of SUDI now having joint home visits.<sup>2</sup> Given the detailed investigation of SUDI, we can be reasonably assured that this study only included deaths that remained unexplained or due to ASSB. Deaths from medical or criminal causes are unlikely to have been misreported as SIDS, unascertained or ASSB; however, this remains a possibility given the limits of current knowledge and expertise particularly as SIDS is a diagnosis based on excluding other causes for death. The inclusion of sleep-related SUDI from birth will have included unexplained infant deaths that may occur shortly after birth.

Our findings are broadly similar to those reported across the European Union, where rates of ASSB range from 0 to 5.5 per 100 000 live births for the period 2005–2015, with the UK reported as 3.0 per 100000.<sup>22</sup> However, this combined all deaths from ICD-10 codes W75-84, many of which will not have occurred in a sleep environment such as deaths of infants from choking on food. The low rates of W75-84 could reflect that much of the European Union does not have robust SUDI investigation, in keeping with best international practice.<sup>23</sup> France requires all SUDI cases to be referred to specialist regional hospitals for investigation, although provision of death scene investigation is variable.<sup>24</sup> In Norway, providing there are no criminal concerns, parents are offered voluntary death scene examination by forensic investigators.<sup>25</sup> In the Netherlands, a statutory process for detailed review of child deaths is yet to be established.<sup>26</sup> It is likely in Europe that cases of ASSB may not be identified as this diagnosis relies on circumstantial rather than pathological findings.

Although England has robust data collection on child deaths in the NCMD, this has not yet reliably reported infant deaths from ASSB. A recent NCMD analysis of SUDI and childhood did not record any deaths from ASSB.<sup>2</sup> The NCMD trauma report recorded 13 infant deaths from suffocation and strangulation but this included non-sleep-related incidents such as strangulation by blind cords.<sup>27</sup> Data from Welsh Child Death

Reviews do not show ASSB deaths separately from other causes.  $^{\ensuremath{^{28}}}$ 

The low rates of ASSB found in this study are in sharp contrast to New Zealand and the USA, where there has been considerable investment in SUDI investigation including death scene analysis. Analysis of death certification data in the USA showed ASSB rates increased from 3.4 per 100 000 live births in 1993 to 23.0 in 2015, while overall sleep-related SUDI decreased from 154.6 to 92.4 per 100 000 live births.<sup>29</sup> This could well be an overestimation of ASSB due to potential conflation of risk factors for SIDS, such as hazardous cosleeping environments, as cause of death. In comparison, an analysis of data from US Child Death Review teams, using detailed case information determined that 899/4929 (18%) of sleep-related SUDI were due to ASSB (17.7 per 100000 live births).<sup>30</sup> This may still be an overestimate due to potential overinterpretation of risk factors such as softbedding as causal for ASSB. SIDS infants are commonly found face down in bedding despite being fully able to turn their head to the side, this is hypothesised to represent a failure of autoresuscitation in response to hypoxia or hypercarbia.<sup>31</sup> An infant dying face-down in soft bedding may well be SIDS and not ASSB. Accurate data for ASSB may come from the New Zealand SUDI case-control study where all cases had detailed death scene analysis conducted by health trained investigators, paediatric postmortem examination and multiprofessional case conferences. They reported 20/137 (14.5%) SUDI cases were attributed to ASSB.<sup>32</sup> Given the much higher rates of ASSB recognised in countries with detailed death scene analysis, it is probable that in England and Wales, we are not identifying such deaths and labelling them as unexplained instead.

Correctly recognising deaths from ASSB, while avoiding overdiagnosis is important. The San Diego SIDS definition<sup>3</sup> is open to (mis)interpretation as category II SIDS includes deaths with 'mechanical asphyxia or suffocation ... not determined with certainty', particularly as it is not possible to prove asphyxia or suffocation at postmortem examination.<sup>7</sup> The triple risk model hypothesises that SIDS occurs when an intrinsically vulnerable infant is exposed to an external stressor during a critical period of development.<sup>33</sup> Infants dying from ASSB do not need to be intrinsically vulnerable, the hazardous situation alone leads to death; these infants are, therefore, not the same as SIDS infants, so research combining both ASSB and SIDS deaths could be misleading. Inconsistent classification of infant deaths is likely to hamper research efforts and interpretation of risk factors<sup>34</sup> and prevent meaningful comparison between countries.<sup>35</sup> One aim of the original SIDS diagnosis was to assist research by enabling similar unexplained infant deaths to be studied. International consensus on standardising the diagnosis of ASSB could also be beneficial, by avoiding overdiagnosis but empowering accurate recognition based

on death scene examination and detailed caregiver accounts. Death scene examination should include photography as this enables the scene findings to be accurately recorded.<sup>36</sup> Although the use of dolls for re-enactment is often recommended,<sup>36</sup> these should be used with some caution as there is considerable potential for distress.<sup>37</sup> Greater diagnostic accuracy would enable further research efforts into both SIDS and ASSB.

Rates of unexpected infant deaths fell significantly from the 1990s with the safe sleep campaigns but have now plateaued in many countries,<sup>22 29</sup> and deaths now occur increasingly in vulnerable socially deprived infants.<sup>20</sup> An in-depth review of English SUDI cases with serious child safeguarding concerns identified hazardous cosleeping in 38/40 with several involving parental drug or alcohol misuse and mental health problems.<sup>38</sup> The review concluded that highrisk families, need tailored information and support to implement safe sleep practices. It is also important to discuss the potential risks of accidental suffocation in some sleep environments. It can be easier for parents to understand risks of accidental suffocation, with clearly describable mechanisms such as airway obstruction or chest compression, than the complex interplay of intrinsic vulnerability and external stressors in SIDS. However, it is difficult for professionals to have these discussions with families if we cannot acknowledge the frequency with which deaths from ASSB take place. We need to empower professionals to have meaningful, supportive conversations with families, and accurate knowledge and understanding of risks, causes and mechanisms for infant deaths is the basis of these discussions. We also should recognise that despite robust investigation some infant deaths remain unexplained even in unsafe sleeping environments, and overdiagnosing ASSB is not helpful and could potentially increase parents distress given that self-blame is a common feature of parental grief.<sup>39</sup>

We need to remove barriers to identifying deaths from ASSB, as under-recognition hinders research and prevention efforts. The standard of SUDI investigation in England has improved over the last few years.<sup>2</sup> The multiagency guidance for investigating SUDI in England<sup>1</sup> is about to be updated, as part of this the conclusions of multiagency SUDI investigations should be better integrated with coroners inquests to enable accurate death certification. We need to develop practical standards for diagnosing ASSB, based on death scene examination and carers accounts. This would probably lead to a diagnostic shift away from unexplained infant deaths, so it would be important to include ASSB in future monitoring of SUDI statistics. Clear, national guidance on classification of SUDI will promote effective research, inform families and help prevent future deaths.

# **Open** access

## Twitter Joanna Jane Garstang @jogarstang

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Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Ethics approval Ethical approval was not required for this project as it only used publicly available data from the Office of National Statistics (England and Wales).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. Original data are publicly available from Office for National Statistics or from the corresponding author on request.

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#### **ORCID iDs**

Joanna Jane Garstang http://orcid.org/0000-0001-9268-0581 Marivjena Menka http://orcid.org/0000-0002-1966-2333

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