How reliable are SIDS rates?

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There is increasing concern with using SIDS as a diagnosis, especially where the postmortem examination reveals additional findings that may be contributory to the death exclusion. This report shows how varying the criteria for a diagnosis of SIDS significantly alters the SIDS rate in Ireland.

The sudden and unexpected death of an infant (SUDI) results in a mandatory postmortem examination in most western countries. Where no adequate cause of death is found, the term sudden infant death syndrome (SIDS) is generally applied and is widely accepted as a natural cause of death. However, in many SIDS cases, there are additional pathology findings, slightly worrying parental practices (infant co-sleeping with parental alcohol consumption), an unusual history or death scene investigation—all of which could be implicated in the infant’s death.

Many pathologists, and coroners, are dissatisfied using the term SIDS where they cannot definitively rule out accidental, environmental, or unnatural causes of death. Accordingly, the use of the term “unascertained” has risen considerably in some countries, although the term has no agreed definition and is used variably and subjectively. Moreover, there is no international agreement on the definition of SIDS and hence the variability in assigning SUDI cases to either SIDS or unascertained categories renders worldwide comparisons difficult.

The purpose of this paper was to show the deviation in SIDS rates in Ireland by speculating how the deaths may be classified, albeit using factors that are currently being used by pathologists in other countries to assign cases. In a hypothetical exercise, we gradually adjusted the diagnostic criteria so that deaths were transferred from the SIDS group to the category of unascertained, resulting in a significant shift in the reported SIDS rate in Ireland.

METHODS

The data are part of an ongoing study of SIDS in the Republic of Ireland and are compiled by the National Sudden Infant Death Register (NSIDR) as described previously. Information collated from the years 1994–2000 was analysed to establish the cause of death, the presence of additional pathology and history, or circumstances surrounding the death which may be a potential factor in labelling the death “unascertained”. Seven variables were identified, some of which are currently (and inconsistently) being used by pathologists to categorise a SUDI as “unascertained” rather than SIDS.

Starting with all SUDI in Ireland (1994–2000), the cause of death as certified on the death certificate was initially used to establish the baseline SIDS and “unascertained” death rates (fig 1, column 1). Subsequently, the seven variables were included sequentially in a stepwise manner to the criteria required for a diagnosis of “unascertained” in order to assess the effect on the SIDS death rate (fig 1; see footnote for definition of variables).

RESULTS

There were 360 304 live births registered in Ireland during the years 1994–2000. A total of 315 cases of SUDI (<32 weeks) were registered with the NSIDR during this period. In 93% of cases (n = 293), the postmortem examination reports were available for analysis. Following the postmortem examination, a cause of death was found for 9.2% of cases (n = 27), 87.4% (n = 256) were diagnosed as SIDS, and in 3.4% (n = 10), the cause of death was originally classified as “unascertained”. In this original classification, the SIDS rate was 0.71 and the unascertained rate was 0.03 deaths/1000 live births. When cases in which there was additional pathology stated in the postmortem examination report were included in the unascertained group, the SIDS rate dropped to 0.55 and the unascertained rate increased to 0.19. As additional variables were sequentially included in the criteria for “unascertained”, the SIDS rate was finally reduced to a low of 0.08 (fig 1). The rate of unascertained deaths was correspondingly increased to 0.66 deaths/1000 live births.

DISCUSSION

In this report, we have shown how the rate of SIDS within one country would fall significantly if the defining criteria were subjectively altered. While overseas the use of the term “unascertained” was increasing during this period, in Ireland the term SIDS was still being widely used by pathologists as the number of SUDI cases originally categorised as SIDS was in excess of 87%. Additionally, some SUDI cases were being classified as SIDS without a death scene investigation or adequate postmortem examination, raising valid concerns about diagnostic accuracy.

The rates of SIDS internationally have been decreasing, primarily as a result of “back to sleep” campaigns, although the reduction in rates has not been equal in different ethnic and socioeconomic groups. Nevertheless, some discrepancy in rates is perhaps generated by pathologists with varying practices in the way they interpret their additional findings, what they feel constitutes an “adequate cause of death”, and they way in which they conclude their results. The potential for inconsistency exists as much between practitioners as it does between countries.

It is noteworthy that according to WHO statistics, the Irish incidence of SIDS ranks eighth highest internationally, yet when the cause of death statement was redefined by excluding from the SIDS category those cases in which there was additional history or postmortem examination findings, the SIDS rate was gradually reduced to one of the lowest on record.

Abbreviations: NSIDR, National Sudden Infant Death Register; SIDS, sudden infant death syndrome; SUDI, sudden and unexpected death of an infant

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Consequently, this highlights the need for international standardised exclusion criteria and definitions for pathologists performing SUDI postmortem examinations to correct the variance in SIDS rates among different countries. The investigation of these deaths also requires a multidisciplinary team approach, maximising the expertise in classifying these cases to accurately differentiate natural from unnatural infant deaths and to identify further epidemiological risk factors for SIDS.

**Variables added to unascertained criteria**

*Additional pathology findings included for example, oesophagitis, bronchiolitis, or peri-tracheal inflammation. Co-sleeping was defined as any shared sleeping arrangement of an infant with an adult in or on a bed/sofa/armchair. Illness and symptoms reportedly experienced by the infant in the 48 hours prior to death included respiratory, gastrointestinal, and feeding problems, infections, vaccinations, and central nervous system problems. Behavioural changes included fluid intake, urine output, sleeping, crying, arousal patterns, and responsiveness (less or more than usual).

**Figure 1** Changing the rate of SIDS. The SIDS rate during the period 1994–2000 in Ireland was 0.71 per 1000 live births. When additional variables* were sequentially included in the criteria for “unascertained”, the SIDS rate was gradually reduced to a low of 0.08 per 1000 live births.

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