

CURRENT PEDIATRIC REVIEWS

International Trends in Sudden Infant Death Syndrome and Other Sudden Unexpected Deaths in Infancy: Need for Better Diagnostic Standardization

Fern R. Hauck, M.D., M.S.,^{1,2} Kawai Tanabe, M.P.H.¹

Departments of Family Medicine¹ and Public Health Sciences²

University of Virginia School of Medicine, Charlottesville, VA, USA

Correspondence to:

Fern R. Hauck, M.D., M.S.

Associate Professor of Family Medicine and Public Health Sciences

Department of Family Medicine

University of Virginia School of Medicine

P.O. Box 800729

Charlottesville, VA 22908-0729

USA

Tel: 434-924-5451; Fax: 434-243-4800; Email: frh8e@virginia.edu

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Abstract

Purpose: The aim of this paper is to compare international trends in sudden infant death syndrome (SIDS) and postneonatal mortality (PNM) since the introduction of SIDS risk reduction and safe sleep campaigns, offer possible explanations for differences, and to provide recommendations to improve consistency in classifying and reporting infant SUDI deaths internationally.

Methods: SIDS and postneonatal mortality rates were obtained for 15 countries from 1990 through the year for which most recent data were available.

Results: SIDS rates have declined in all countries, with reductions well over 50% for most countries. These declines are attributed to SIDS risk reduction campaigns, which achieved success primarily in reducing rates of prone sleeping among infants. The largest declines generally occurred in the first few years after initiation of national campaigns, and there are concerning indications that these rates have reached plateaus in many countries.

Conclusions and Recommendations: Diagnostic accuracy is essential to monitor and compare trends in SIDS and other sudden unexpected infant deaths. This requires establishing sudden infant death definitions and diagnostic categories that are agreed upon widely. National and local campaigns need to be re-energized to continue the early successes made in reducing SIDS incidence. Finally, data collection needs to be easy to access and this would best be accomplished by national vital statistics agencies posting data in a uniform way on their websites.

Background

Sudden unexpected death in infancy (SUDI) describes all sudden, unexpected infant deaths regardless of cause. SIDS is a subset of SUDI, and is defined as the sudden death of an infant less than 1 year of age that is unexpected by history and unexplained after a thorough autopsy, including investigation of the scene of death and review of the medical history.¹ In the U.S., there are approximately 4,600 SUDI deaths a year, and there were 2,323 SIDS deaths in 2006, accounting for approximately half of the SUDI deaths.² Other causes of SUDI include illnesses that are explained by findings from the autopsy and scene investigation, such as infection, infanticide, inherited disorders of fatty acid metabolic and cardiac channel defects. Suffocation in bed and other suffocation, considered “explained” causes of death now account for a growing proportion of SUDI. “Indeterminate”, “undetermined” or “unknown” cause of death are likewise being more frequently used as causes of death.³⁻⁶ SIDS and SUDI largely occur in infants older than 1 month, i.e., in the postneonatal period. Since assignment of cause of death is known to vary within and across countries in cases of SUDI, the use of the PNM rate may be a better indicator of trends in SIDS and other SUDI. The aim of this paper is to compare international trends in SIDS and postneonatal mortality (PNM) since the introduction of SIDS risk reduction and safe sleep campaigns, offer possible explanations for differences, and to provide recommendations to improve consistency in classifying and reporting infant SUDI deaths internationally.

Methods

Data were collected in two cycles. For the first cycle (data through 2005), national SIDS and postneonatal mortality rates were collected from several sources, including websites from national vital statistics centers and correspondence with statisticians provided on those websites; published reports; and through correspondence with leading SIDS researchers in several countries, who, in turn, collected the data from their respective national registries or vital statistics offices.⁷ The second cycle, which added two countries not included in the first cycle (Austria and France), updated the information to the most recent year available. Members of the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) were contacted and asked to provide these data. Not all members responded, even though they were contacted several times. The year that each country's SIDS risk reduction campaign began was also provided, along with the ages of inclusion for the SIDS diagnosis, since these can vary by country.

Results

SIDS data were obtained for 15 countries (Table 1). For most of these countries, there has been a large decrease in SIDS rates from 1990 to the most recent year available (2005-2008). These decreases range from 40% in Argentina to 86% in France. The highest SIDS rates in 1990 ($\geq 2.0/1000$ live births) were in Ireland, New Zealand, and Scotland. More recently, the highest SIDS rates ($\geq 0.5/1000$ live births) are in New Zealand and the United States. The lowest rates ($\leq 0.2/1000$) are in Japan and the Netherlands. The largest decrease in SIDS rates from baseline, which for most countries was before risk reduction campaigns began in the early 1990s, occurred by 2000.

Declines in PNM rates have occurred for all the countries, with the smallest decline in Japan (30%) and the largest in Ireland (73%). Generally, the relative declines in postneonatal mortality rates are smaller than those for the SIDS rates in each respective country. The highest postneonatal rate is in Argentina and the lowest are in Austria, Ireland, and Norway.

The decline in SIDS is mirrored by a decline in postneonatal mortality, with greater declines occurring earlier in the risk reduction campaigns (Figure 1). This provides evidence that the SIDS declines have been real. Different patterns have emerged, however, in later time periods. For some countries, the declines in SIDS and postneonatal mortality have stabilized in most recent years (e.g., Austria, Ireland, the Netherlands, Sweden, and the U.S.). For some, rates of both continue to decline gradually (e.g. England/Wales and New Zealand).

Table 1. Comparison of international SIDS and postneonatal mortality rates*, 1990-most recent year available

Country	SIDS Ages for Inclusion	1990	1995	2000	2001	2002	2003	2004	2005	2006	2007	2008	Risk Reduction Campaign Began**
Argentina-1 SIDS ^b	Birth to 1 year	0.81	0.76	0.53	0.44	0.58	0.49	0.47	0.49	NA	NA	NA	2003
PNM		9.40	8.12	5.65	5.62	5.58	5.94	4.62	4.49	NA	NA	NA	
Australia-2 SIDS ^a	Birth to 1 year	1.81	0.75	0.51	0.43	0.43	0.29	0.22	0.32	NA	NA	NA	1991
PNM		3.18	1.87	1.73	1.58	1.64	1.45	1.44	1.32	NA	NA	NA	
Austria-3 ^a SIDS	Birth to 1 year	1.56	0.64	0.50	0.30	0.41	0.34	0.20	0.38	0.32	0.29	0.28	1989 ^d
PNM		3.3	2.0	1.5	1.5	1.2	1.3	1.3	1.2	1.0	1.1	1.0	
Canada-4 SIDS ^a	1 week to 1 year	0.81	0.66	0.37	0.34	0.33	0.28	0.24	0.33	NA	NA	NA	1993
PNM		2.21	1.95	1.66	1.43	1.47	1.32	1.28	1.32	1.30	NA	NA	
England/Wales-5 SIDS ^b (Includes SIDS & Undetermined)	1 week to 1 year	1.7	0.61	0.55	0.55	0.50	0.51	0.50	0.50	0.43	0.38	NA	1991
PNM		3.3	2.0	1.7	1.9	1.7	1.7	1.6	1.6	1.5	1.5	NA	
France- 6 SIDS ^b	Birth to 1 year	1.83	0.76	0.46	0.45	0.38	0.34	0.37	0.32	0.32	0.26	NA	1994
PNM		3.8	2.0	1.6	1.6	1.4	1.4	1.3	1.3	NA	NA	NA	
Germany-7 SIDS ^a	1 week to 1 year	1.42	0.98	0.63	0.58	0.51	0.48	0.46	0.43	0.39	0.33	NA	1991 ^e
PNM		3.3	2.1	1.7	1.6	1.5	1.48	1.45	1.40	1.25	1.22	1.18	
Ireland-8 SIDS ^a	Birth to 1 year	2.20	0.64	0.86	0.70	0.57	0.58	0.51	0.38	0.36	0.41	NA	1992
PNM		3.7	1.6	1.9	1.7	1.6	1.3	1.4	1.1	1.1	1.0	NA	
Japan-9 SIDS ^b	Birth to 1 year	0.30	0.44	0.27	0.25	0.22	0.19	0.19	0.16	0.16	0.13	NA	1998
PNM		2.0	2.1	1.4	1.5	1.3	1.3	1.3	1.4	1.3	1.3	NA	
The Netherlands-10 SIDS ^a	Birth to >1 year	0.56	0.25	0.12	0.17	0.11	0.14	0.09	0.10	0.06	NA	NA	1987
PNM		2.3	1.7	1.2	1.5	1.2	1.2	1.0	1.2	NA	NA	NA	
New Zealand-11 SIDS ^a	Birth to >1 year	2.90	2.09	1.10	0.90	0.80	1.09	1.24	0.80	NA	NA	NA	1991

Country	SIDS Ages for Inclusion	1990	1995	2000	2001	2002	2003	2004	2005	2006	2007	2008	Risk Reduction Campaign Began**
PNM		4.21	3.53	2.50	2.60	1.98	2.06	2.60	1.90	NA	NA	NA	
Norway-12 SIDS ^a	Birth to 1 year	1.7	0.48	0.44	0.42	0.34	0.23	0.25	0.30/17	NA	NA	NA	1990
PNM		3.1	1.4	1.2	1.1	1.0	1.0	1.0	1.0	NA	NA	NA	
Scotland-13 SIDS ^a	1 week to 1 year	2.0	0.72	0.62	0.61	0.62	0.82	0.52	0.37	0.48	0.54	0.37	1991
PNM		3.3	2.2	1.8	1.7	2.1	1.7	1.9	1.7	1.4	1.5	1.4	
Sweden-14 SIDS ^a	Birth to 1 year	1.0	0.4	0.3	0.3	0.25	0.24	0.28	0.23	NA	NA	NA	1992
PNM		2.4	1.28	1.07	1.12	1.05	0.88	0.93	0.96	NA	NA	NA	
U.S.A.-15 SIDS ^c	Birth to 1 year	1.30	0.87	0.62	0.55	0.66	0.53	0.55	0.54	0.55	NA	NA	1994
PNM		3.38	2.67	2.28	2.31	2.31	2.23	2.27	2.34	2.24	NA	NA	

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NA = Not available or provisional.

*SIDS rate = number of SIDS deaths/1,000 live births; Postneonatal mortality rate = number of infants who died ≥ 28 days/1,000 live births.

**The year the respective “official” national campaign began. In some countries, regional campaigns began one or more years before the national campaign.

^a The number of SIDS deaths in most recent year was <100

^b The number of SIDS deaths in most recent year was 100 – 999

^c The number of SIDS deaths in most recent year was ≥ 1000

^d Systematic risk reduction campaigns began at different times in different regions (federal states) between 1989 (Styria, the Tyrol) and 1998 (Vienna). Furthermore, different risk reduction campaigns were slightly different concerning contents and employed methods.

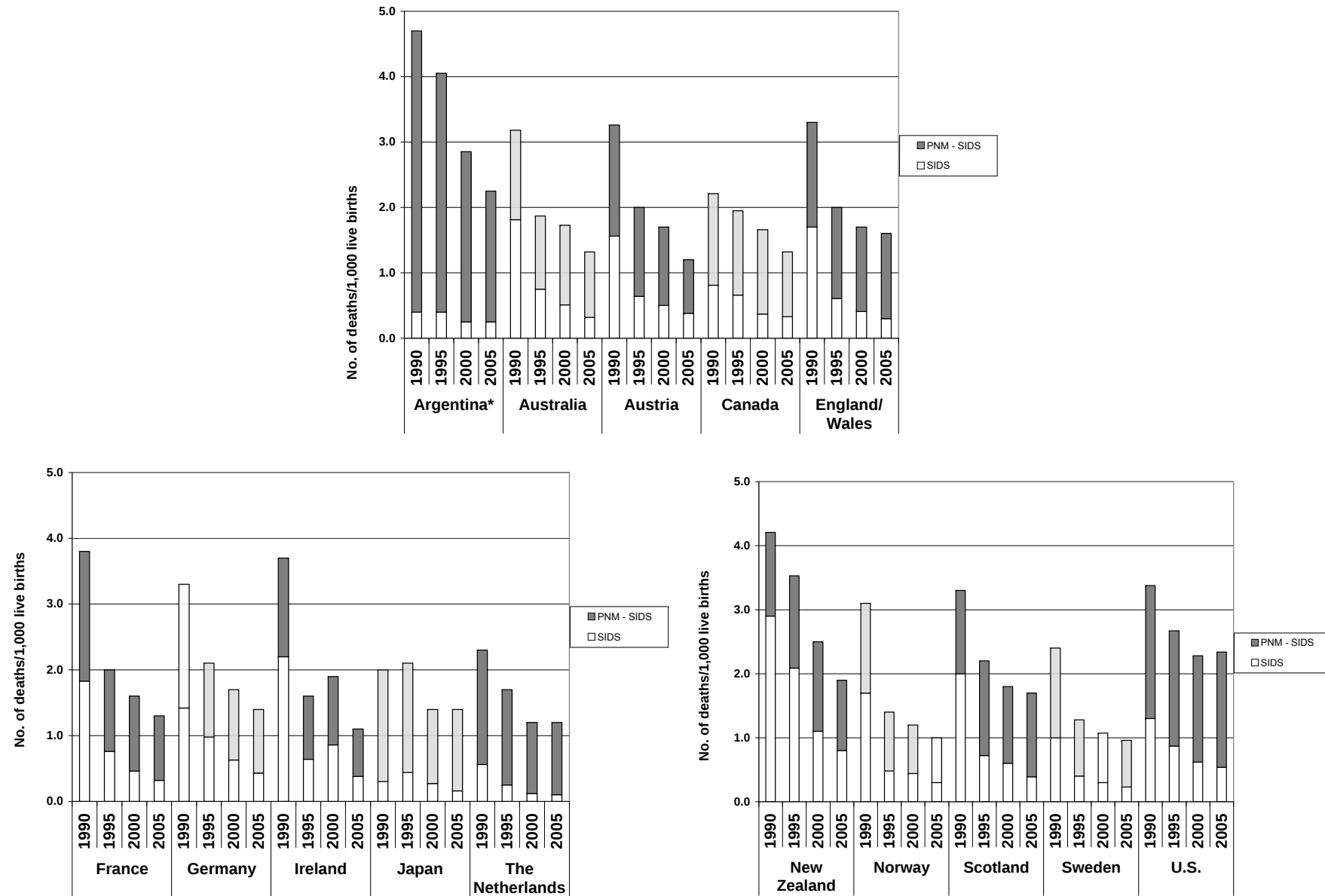
^e There has not been a nationwide campaign in Germany, but individual regions have conducted campaigns. The first was in Northrhine-Westfalia, beginning in 1991.

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4. Statistics Canada, www.statcan.ca and Canadian WHO Statistical Information Services, www.who.int/healthinfo/statistics
5. Office for National Statistics, www.statistics.gov.uk; Foundation for the Study of Infant Deaths, www.fsid.org.uk/Page.aspx?pid=191
Justification for the use of undetermined in addition to SIDS in the rates is found in: www.fsid.org.uk/Document.Doc?id=97
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Postneonatal data: INSEE : Institut national de la statistique et des études économiques, www.insee.fr/fr/themes/detail.asp?ref_id=ir-sd2006&page=irweb/sd2006/dd/sd2006_mortalite.htm
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Figure 1. Postneonatal Mortality and SIDS Trends, 1990 – 2005



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*Rates are halved to keep comparison with other countries on the same scale

Discussion

SIDS rates have declined in all countries for which data were obtained, with reductions well over 50% for most countries. These declines are attributed to SIDS risk reduction campaigns, which achieved success primarily in reducing rates of prone sleeping among infants.⁸⁻²⁰ The largest declines generally occurred in the first few years after initiation of national campaigns. Declines were also found in postneonatal mortality rates in most countries. This would be expected, as the majority of SIDS deaths occur in the postneonatal period, and supports the decline in SIDS being real - especially the early declines - rather than being the result of classifying SIDS as other causes of death.

Rates of SIDS, however, differ considerably across countries, ranging from 0.10/1000 live births to 0.80/1000 in 2005. There are several possible explanations for these differences:

Age of Inclusion for SIDS. The age of inclusion for SIDS differs across countries. Some countries (Canada, England and Wales, Germany, and Scotland) define SIDS as occurring from one week to one year. Other countries include infants from birth to one year (Argentina, Australia, Austria, France, Ireland, Japan, Sweden, and the U.S.) or birth to over one year (the Netherlands and New Zealand). This may account for at most a small difference in SIDS rates since the number of SIDS deaths occurring in the first week of life and after one year are very small.²¹⁻²³

SIDS Definition. Different definitions of SIDS also contribute to the variation in rates seen not only across countries but within countries. In a recent study by Byard and Marshall, 50 papers published in 2005 were reviewed in which the validity of the conclusions depended on accurately defining SIDS.²⁴ One of five definitions were searched for in each paper: the 1969 Seattle definition (Beckwith 1970),²⁵ the NICHD definition (Willinger 1991),¹ the San Diego definition (Krous 2004),²⁶ those that used a

non-standard definition, and those where no definition was provided. The authors found that over half (58%) of the papers had used a non-standard definition or provided no definition, concluding that a standard definition of SIDS is needed to ensure validity of research data and comparability of data across centers.

Death Scene Investigation and Autopsy Protocols and Determination of Cause of Death. The content and use of death scene investigation and autopsy protocols in cases of sudden unexpected infant death vary across different locales. While standard protocols have been recommended internationally and nationally,²⁷⁻²⁹ local conditions determine what and how extensively they are applied. For example, autopsy rates are lower in the Netherlands³⁰ and Japan³¹ compared with other countries. Without a thorough autopsy, investigation of the location of death, and review of pertinent medical history, it is difficult to distinguish between SIDS and other causes of SUDI.

Even with similar definitions and protocols, there can be large differences in assignment of cause of death, with some pathologists under-diagnosing SIDS and others applying the diagnosis too liberally.³² Further, there is evidence that with implementation of more comprehensive autopsy and scene investigation protocols, there have been shifts in the classification of the cause of death within countries. This “diagnostic shift” has been found in South Australia,⁴ England and Wales,⁵ and the U.S.,^{3,22,29} where the use of the SIDS diagnosis declined while there was an increase in deaths attributed to accidents or classified as “undetermined.”⁽¹⁾ Shapiro-Mendoza and colleagues found that from 1999-2001, the decline in SIDS rates in the U.S. was offset by increased rates of cause unknown/unspecified and accidental suffocation and strangulation in bed. Infant mortality rates attributable to the other causes of sudden unexpected death, i.e., other accidental suffocation and strangulation, and neglect, abandonment and other maltreatment syndromes, remained unchanged. The authors

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⁽¹⁾ This refers to ICD category “unknown and unspecified;” it is also called “undetermined” or “unascertained.” The ICD-9 code was 799.9 and ICD-10 is R99.

also examined risk factors for SIDS and the other SUDI for the various time periods examined, and found that the risk factors remained stable over time and were common to all the SUDI infants, suggesting that the decline in SIDS from 1999 to 2001 was not likely a true decline, but related to the way in which these infant deaths were classified.

An investigation in England found that declines in the SIDS rate have been accompanied by increases in the rate of unascertained deaths.⁵ In a study conducted by Limerick and Bacon of pathologists in England who performed infant autopsies in cases of sudden infant death, wide variations were found in the pathologists' use of the terms sudden infant death syndrome and unascertained.³³ Use of the latter was common when infants were sharing a bed with an adult or when suspicious features were present. As a result of these findings, infant deaths certified as SIDS or unascertained in England and Wales are considered "SIDS" for data reporting purposes.³⁴ Additionally, the cause of death may intentionally be misrepresented in order to avoid an autopsy because of local cultural or religious practices³⁵ or to avoid implementation of time-consuming scene investigation protocols.³⁶ These types of classification variations are likely occurring in other countries, where analyses by cause of death need to be conducted to fully understand local trends. Thus, for more recent periods, the "true" decline in SIDS in some countries may be lower than the statistics would imply.

Risk Factors for SIDS. Risk factors for SIDS differ across countries and therefore are likely to contribute to the variability in rates. For example, smoking rates are high among the Maori in New Zealand and American Indians, groups in which the rate of SIDS remains high.^{37,38} Infant prone sleeping rates have declined to single digits in several countries (e.g., in Western Sweden the rate was 5.6% in 2003-2004)³⁹ while remaining higher in others (e.g., in the U.S. prone placement was 11.4% in 2009 for all infants, and 21.6% for black infants).⁴⁰

Introduction of the 10th revision of the International Classification of Diseases (ICD-10) in 1999 could have influenced some of the changes in SIDS rates; the ICD-9 was used from 1979-1998. However, the effect of the new revision is likely to be insignificant. Malloy and MacDorman examined the possible effect of different ICD revisions on trends in cause-specific mortality rates, by adjusting the rates for the major causes of sudden unexpected infant death for the period 1992-1998 under ICD-9 to be comparable to ICD-10 rates.³ The adjusted rates were not significantly different from the unadjusted rates.

Conclusions and Recommendations

There have been significant reductions in SIDS deaths around the world. These declines appear to be real, attributed in large measure to risk reduction activities, especially placing babies supine to sleep.^{9-11,16} However, rates have reached a plateau in the majority of countries and in some the rates remain unacceptably high, underscoring the need for risk reduction activities to be continued, especially in communities with the greatest burden of SIDS.⁴¹ In addition to infant sleep position, other well-established risk factors should receive attention, such as maternal smoking in pregnancy, infant overheating, sleep location (infants sleeping in bed with parents or other individuals), and soft bedding.⁴²⁻⁴⁴ This is especially important in countries that have achieved high supine sleeping rates and which have seen increases in other risk factors, such as smoking among women.^{45,46} Additionally, emerging modifiable risk factors need to be publicized and discussed with families and caregivers of young infants.

Differences in rates and trends are also influenced by diagnostic shifts that have occurred. Prior to 1969, SIDS did not exist as a diagnostic category, and thus sudden unexpected infant deaths were coded inconsistently (and inaccurately). Beckwith proposed the first definition of SIDS in 1969 as the sudden death of an infant or young child, which is unexpected by history, and in which a thorough postmortem examination fails to demonstrate an adequate cause of death.²⁵ The benefits of this designation were many, including recognition of a distinct entity resulting in the investment of resources for bereavement support, research and risk reduction interventions. However, in the 40 years since the first definition of SIDS, we continue to see different interpretations of this and subsequent definitions, including the 1989 National Institute of Child Health and Human Development definition which includes the requirement of a scene investigation.¹ As described previously, one could argue that more widespread

implementation of the scene investigation in cases of sudden unexpected death has led to greater variability in diagnosis, but with uncertain accuracy. For example, some coroners and medical examiners will not use the SIDS diagnosis if the infant had been sleeping in bed with a parent, regardless of the circumstances. These may be diagnosed as asphyxia in bed or unknown cause.⁴⁷

Consequently, several classifications for SIDS and SUDI have been proposed as a way to achieve greater accuracy and consistency in diagnosis within and across countries.^{26,32,48,49} The Nordic Countries have been successful in adopting standard criteria to diminish previously identified discrepancies in SIDS rates.⁵⁰⁻⁵² It is essential that more widespread consensus on the definition and classification of sudden unexpected death in infancy be achieved so that national and international comparisons are more meaningful.⁷ Unfortunately, up to now, it has been difficult to achieve consensus both within and across countries. The World Health Organization's International Statistical Classification of Diseases and Related Health Problems, now in the 10th Revision (ICD-10), may be the best way to achieve such a standard. The current categories encompassing "ill-defined and unknown causes of mortality", where SIDS is found (R95) should be expanded to include subcategories where pertinent contributory information can be taken into account, including pertinent sleep environment factors that may have contributed to the infant's death.⁵³

The collection of SIDS and other infant mortality data internationally needs to be easier. While using the Internet has provided better access to data, in most cases the websites were inadequate to achieve comparisons due to difficulty in locating data, data being located in different reports and sometimes containing conflicting numbers, some years were not available or multiple years were combined, and most websites were not in English. Without the collaboration of SIDS researchers and vital records staff, this project would not have been possible. Further, the results presented in this paper are

limited to the countries from which data were provided or available, and thus do not provide a fully representative profile of international SIDS and postneonatal mortality rates. In the developing world where resources are severely limited, autopsies and scene investigations are not routinely done and other causes of infant mortality predominate, such as infectious diseases.⁵⁴ Studies and methodologies need to be developed to elucidate the extent of SIDS and SUDI within these less developed countries.

Given the challenges outlined above, a first step would be for countries to report annual statistics on the number and rate of SIDS deaths and other categories of SUDI, including asphyxia in bed, asphyxia, and unascertained/unknown cause; the number of live births; the number and rate of postneonatal deaths; the age range for which the SIDS diagnosis is applied; and the definition of SIDS, if one standard is used. Ideally, these would be available on national vital statistics websites in English. International research groups and other bodies should continue to work towards developing a uniform classification of SIDS and SUDI. As noted above, incorporating this into a new ICD classification could help achieve uniform reporting and data collection. Ongoing research is essential to examine the epidemiologic and pathophysiologic mechanisms underlying different categories of sudden infant death to better understand if these are indeed separate entities or one and the same.

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