



## Practice of Epidemiology

### Recent National Trends in Sudden, Unexpected Infant Deaths: More Evidence Supporting a Change in Classification or Reporting

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The recent US decline in sudden infant death syndrome (SIDS) rates may be explained by a shift in how these deaths are classified or reported. To examine this hypothesis, the authors compared cause-specific mortality rates for SIDS, other sudden, unexpected infant deaths, and cause unknown/unspecified, and they evaluated trends in the age and month of death for these causes using 1989–2001 US linked birth/death certificate data. Reported deaths in state and national data were compared to assess underreporting or overreporting. SIDS rates declined significantly from 1989–1991 to 1995–1998, while deaths reported as cause unknown/unspecified and other sudden, unexpected infant deaths, such as accidental suffocation and strangulation in bed (ASSB), remained stable. From 1999–2001, the decline in SIDS rates was offset by increasing rates of cause unknown/unspecified and ASSB. Changes in the cause-specific age at death and month of death distributions suggest that cases once reported as SIDS are now being reported as ASSB and cause unknown/unspecified. Most of the decline in SIDS rates since 1999 is likely due to increased reporting of cause unknown/unspecified and ASSB. Standardizing data collection at death scenes and improving the reporting of cause of death on death certificates should improve national vital records data and enhance prevention efforts.

classification; infant mortality; sudden infant death

Abbreviations: ASSB, accidental suffocation and strangulation in bed; ICD-9, *International Classification of Diseases*, Ninth Revision, Clinical Modification; ICD-10, *International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision; SIDS, sudden infant death syndrome; SUID, sudden, unexpected infant death.

Infant mortality rates due to sudden infant death syndrome (SIDS) declined 57.4 percent from 1990 through 2001. Despite this decline, SIDS remains the third leading cause of infant mortality in the United States. Much of the decline has been attributed to a decrease in prone sleeping (1, 2). More recently, researchers have hypothesized that the continued decline may be due to changes in reporting or diagnostic practices, but there is limited evidence to support this idea (1, 3–5). To accurately assess the risk factors associated with SIDS and other sudden, unexpected infant deaths (SUIDs), we need to better understand how these deaths are being classified and reported.

SIDS is defined as “the sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history” (6, p. 681). Even with a thorough death scene investigation, review of the clinical history, and autopsy, SIDS is difficult to distinguish from other SUIDs, such as accidental suffocation and asphyxia (7).

A recent study assessing US postneonatal mortality rates provided some evidence supporting a change in classification (5). The authors suggested that the greater than 90 percent decline in postneonatal mortality attributable to SIDS

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in 1999–2001 can be explained by the increasing rates of other causes of SUIDs. However, in light of a 25 percent increase in the proportion of SIDS deaths occurring in the neonatal period (from 6.4 percent of all SIDS deaths in 1989–1991 to 8.0 percent in 1999–2001), it is important to assess all infant deaths and not just those occurring in the postneonatal period.

In this study, we assessed trends in rates of SIDS, other SUIDs, and cause unknown/unspecified using linked birth and death certificate data for all infant deaths. Additionally, we examined the cause-specific age at death and month of death distributions. If the age at death distribution for other SUIDs and cause unknown/unspecified has become more similar to that of SIDS, this would support the hypothesis that cases once reported as SIDS are now being reported as other SUIDs and cause unknown/unspecified. Additionally, if the seasonal distribution of SIDS cases were less pronounced (8, 9) and more like that of other SUIDs and cause unknown/unspecified, this would also support our hypothesis.

## MATERIALS AND METHODS

We used the US period “Linked Birth/Infant Death Data Set” to analyze infant mortality attributable to SIDS, cause unknown/unspecified, and other SUIDs from 1989 through 2001, except for the years 1992–1994 when linked data files were not available (10). Our analysis included only infants born to US residents.

Cause-specific infant mortality rates (the number of infant deaths for a specific underlying cause-of-death category per 100,000 livebirths) were calculated for SIDS, other causes of SUIDs, and cause unknown/unspecified. We derived the cause-of-death data from the underlying cause of death reported on the death certificate. Codes for cause of death were defined according to the *International Classification of Diseases*, Ninth Revision, Clinical Modification (ICD-9) (11), and the *International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision (ICD-10) (12). We used guidelines from the National Center for Health Statistics to determine the comparability between ICD-9 and ICD-10 codes (13).

We combined the years 1989–1991, 1995–1998, and 1999–2001 because of the unique historical significance of these time periods and because combining these years gave us a larger sample size that allowed for more stable estimates. The years 1989–1991 represent the time before prone sleeping for infants was widely discouraged by the medical community. The years 1995–1998 represent the time immediately after the 1992 American Academy of Pediatrics recommendations (2) and the commencement of the national educational campaign that both encouraged nonprone sleeping. The years 1999–2001 represent the most recent data available, and they reflect the ICD-10 coding system for the cause of death reported on the death certificate.

Approximately 5 percent of all infant death certificate records are transmitted to the National Center for Health Statistics with the cause of death designated as “pending investigation.” In some cases, a tentative cause of death is reported, but more often the cause-of-death section is left

blank. At file closure, records still pending investigation are assigned the tentative cause of death, or if no tentative cause is reported, the cause of death is coded as cause unknown/unspecified (ICD-9 code 799.9 and ICD-10 code R99). The implementation of ICD-10 resulted in delays or failures to transmit amendments to the National Center for Health Statistics, especially for data years 1999–2001 (R. N. A., unpublished data). Consequently, the number of records with pending investigations at file closure increased considerably during this time.

After looking at all causes of SUIDs, we chose to focus our cause-specific infant mortality analysis on the deaths reported as cause unknown/unspecified and the leading causes of SUIDs: SIDS; accidental suffocation and strangulation in bed (ASSB); other accidental suffocation and strangulation; and neglect, abandonment, and other maltreatment syndromes. We used the Cochran-Armitage test for linear trend to estimate the statistical significance ( $p < 0.05$ ) of observed patterns over time for each cause of death. For each time period, we calculated cause-specific mortality rates and used Poisson regression to determine the percentage change in the rate between earlier and recent time periods. We used  $z$  values and corresponding 95 percent confidence intervals from the Poisson regression to assess the precision of the percent changes. Reporting confidence intervals and using formal statistical methods are appropriate when assessing and comparing national trends in infant mortality (14–16). Even though the numbers of infant deaths and livebirths represent complete counts and are not subject to sampling error, the data may still be affected by random fluctuations in the number of events from year to year. The effect of such random fluctuations on infant mortality rates is proportionately larger when the number of events is small.

Because the cause unknown/unspecified and ASSB rates have increased significantly in recent years and had the next highest cause-specific infant mortality rates after SIDS, we compared percent distributions and rates of SIDS, cause unknown/unspecified, and ASSB by time period, age at death, month of death, and sociodemographic risk factors. A chi-square test for general association was used to measure differences in the percent distributions of age at death and month of death for the earlier and later time periods. Data were analyzed using STATA statistical software, version 8 (Stata Corporation, College Station, Texas). All tests of statistical significance were two sided.

## RESULTS

Of the 111,191 reported infant deaths in 1989–1991, SIDS accounted for 14.4 percent of all infant deaths, while cause unknown/unspecified and SUIDs accounted for 3.2 percent. In contrast, of the 82,171 reported infant deaths in 1999–2001, SIDS accounted for 8.9 percent, while cause unknown/unspecified and SUIDs accounted for 5.7 percent. Table 1 provides the frequency of cause-specific mortality, the cause-specific mortality rates, and the percent change in these rates over the study period. SIDS rates declined by 22 percent from 1995–1998 to 1999–2001 (from 77.4 to 60.8 SIDS deaths per 100,000 livebirths). The rates of the other

**TABLE 1. Infant mortality rates for sudden infant death syndrome, cause unknown/unspecified, and three leading causes of sudden, unexpected infant deaths, by cause of death and year, United States, 1989 through 2001\***

Cause of death (ICD-9†/ICD-10‡ code) (11, 12)	Frequency of infant deaths			Infant mortality rates (per 100,000 livebirths)			Comparing rate in 1989–1991 with rate in 1995–1998		Comparing rate in 1995–1998 with rate in 1999–2001	
	1989–1991 (n = 111,191)	1995–1998 (n = 111,848)	1999–2001 (n = 82,171)	1989–1991	1995–1998	1999–2001	% change	95% CI†	% change	95% CI
SIDS‡ (798.0/R95)	16,027	12,086	7,323	130.2	77.4	60.8	–41	–42, –39	–22	–24, –19
Cause unknown/unspecified and SUID‡, †	3,558	4,474	4,684	29.2	28.8	39.0	–2	–6, –3	35	30, 41
Cause unknown/unspecified (799.9/R99)	2,427	2,854	2,947	19.7	18.3	24.5	–7	–12, –2	34	27, 41
Accidental suffocation and strangulation in bed (E913.0/W75)	408	636	905	3.3	4.1	7.5	23	9, 39	85	67, 104
Other accidental suffocation and strangulation (E913.1–E913.9/ W76–W77, W81–W84)	315	534	491	2.6	3.4	4.1	34	16, 54	19	5, 35
Neglect, abandonment, and other maltreatment syndromes (E967, E968.4/Y06–Y07)	446	470	350	3.6	3.0	2.9	–17	–27, –5	–4	–16, 11
Combined SIDS, cause unknown/ unspecified, and SUID‡	19,570	16,554	11,997	159.4	106.2	99.8	–33	–35, –32	–6	–8, –4

\* Cause-specific infant mortality rates per 100,000 livebirths. Data were calculated from a US period “Linked Birth/Infant Death Data Set” (10). No linked data files are available for the years 1992–1994.

† ICD-9, *International Classification of Diseases*; Ninth Revision, Clinical Modification; ICD-10, *International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision; CI, confidence interval; SIDS, sudden infant death syndrome; SUID, sudden, unexpected infant death.

‡ SUID includes accidental suffocation and strangulation in bed; other accidental suffocation and strangulation; and neglect, abandonment, and other maltreatment syndromes.

three major causes of SUIDs (i.e., ASSB; other accidental suffocation and strangulation; and neglect, abandonment, and other maltreatment syndromes) and cause unknown/unspecified, taken together, increased by 35.4 percent (from 28.8 to 39.0 deaths per 100,000 livebirths). Among the three leading causes of SUIDs other than SIDS, the most significant increase was in ASSB (84.5 percent). Comparing the earlier and later periods, we found that the ASSB rates have more than doubled from 3.3 to 7.5 deaths per 100,000 livebirths. Deaths reported as cause unknown/unspecified increased significantly by 33.9 percent.

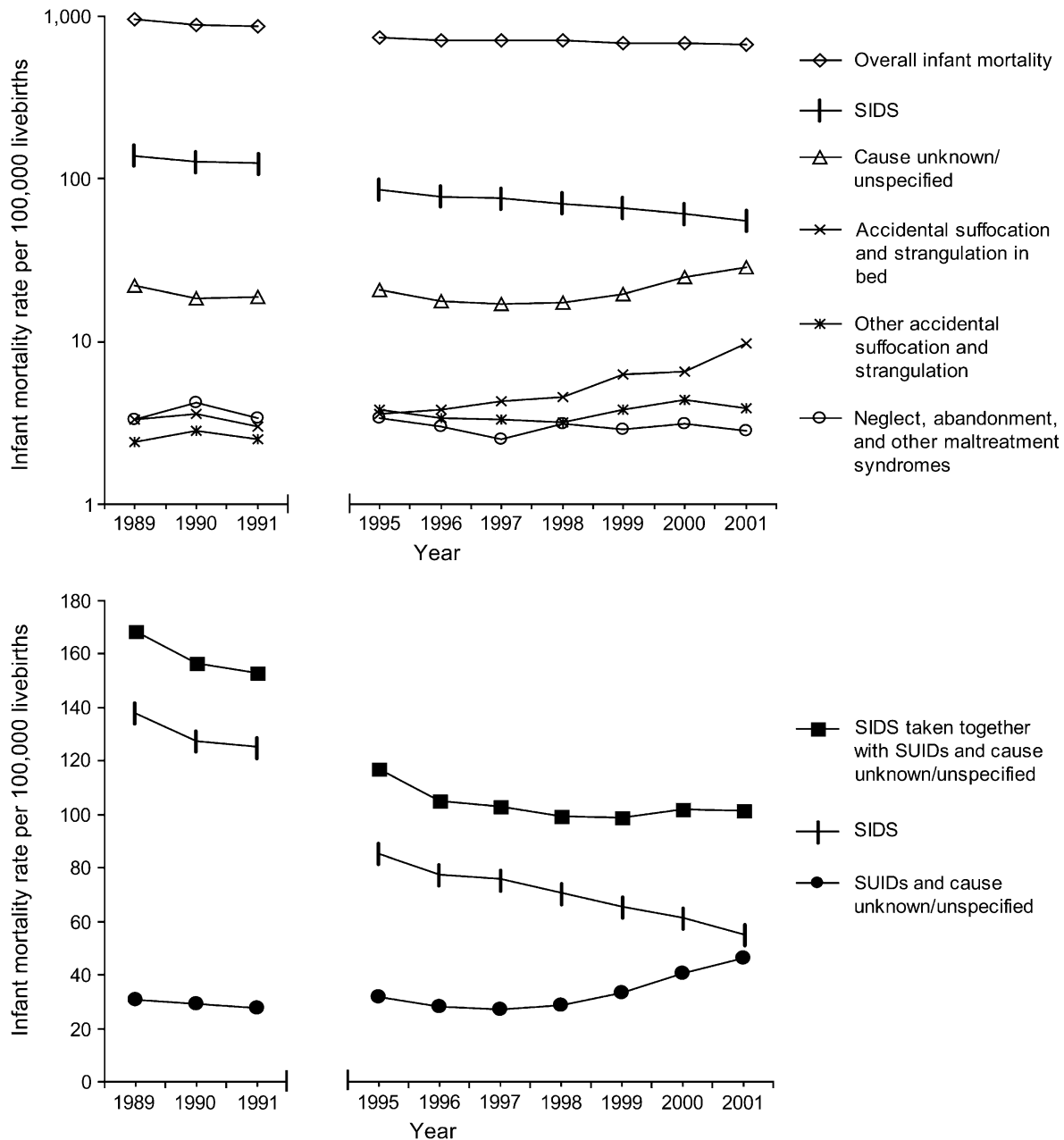
Between 1989 and 2001, infant mortality rates for SIDS were higher than for the other three major causes of SUIDs and cause unknown/unspecified (figure 1, top). SIDS rates declined significantly from 1995 to 2001, while rates due to cause unknown/unspecified and ASSB increased significantly ( $p < 0.001$ ). Infant mortality rates attributable to the other major causes of SUIDs remained nearly unchanged. From 1998 to 2001, the absolute SIDS rate declined by 15.7 deaths per 100,000 livebirths, while cause unknown/unspecified and ASSB rates increased by 11.2 and 5.1, respectively. Figure 1 also shows that the decline in the SIDS rate was offset by an increase in the rate of other SUIDs and cause unknown/unspecified. When we combined all deaths due to SIDS, the three leading causes of SUIDs, and cause unknown/unspecified, we found that the declining trend in the combined rate closely resembled that of the SIDS rate until 1998 (figure 1, bottom). After 1998, this combined rate did not decline or increase, unlike the SIDS rate that continued to decline.

### Age at death

Comparing the age at death distribution for each cause from 1989–1991 to 1999–2001, we found a statistically significant change ( $p < 0.001$ ) in the distributions for SIDS and ASSB but not for cause unknown/unspecified ( $p = 0.732$ ) (figure 2). In recent years, the age distribution of ASSB has become more similar to that of the SIDS distribution. Most of the change in the age distributions for these selected causes occurred between 1 and 4 months of age. SIDS deaths peaked among infants 2–4 months of age during all time periods. However, for SIDS, the most substantial changes in the age distribution were a decline among infants 3–4 months of age and an increase among infants 1 month of age and those aged 6 or more months. For ASSB, there was a substantial increase in deaths among infants 1–3-months of age balanced with a decline in deaths among those aged 4–12 months.

### Month of death

Comparing the month of death distributions for each cause from 1989–1991 to 1999–2001, we found a statistically significant change ( $p < 0.001$ ) in the distributions for SIDS and cause unknown/unspecified (figure 3). ASSB did not follow a seasonal pattern over any of the time periods ( $p = 0.205$ ). During 1989–1991, the month of death distributions for SIDS and cause unknown/unspecified were nearly



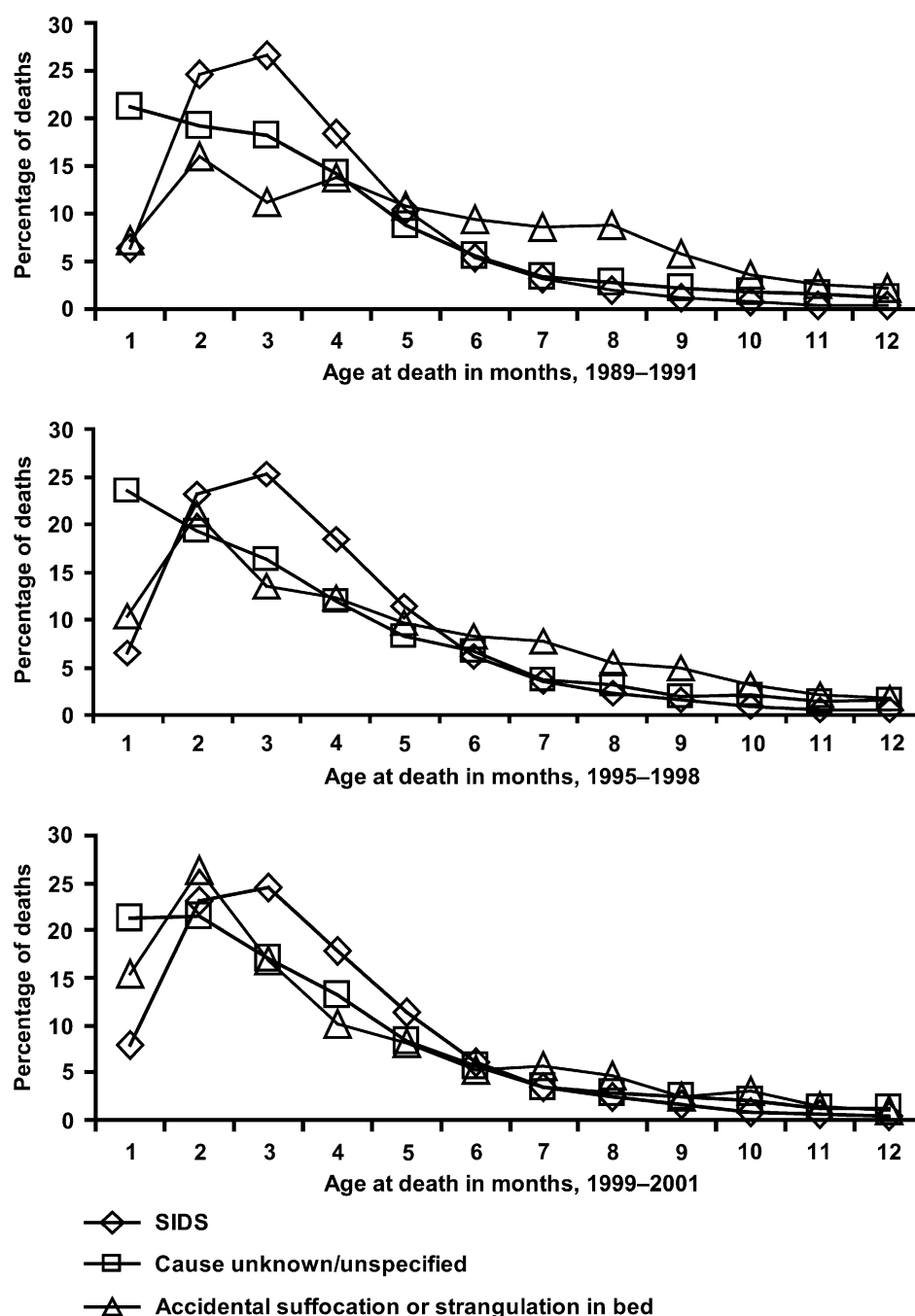
**FIGURE 1.** Infant mortality rates due to sudden infant death syndrome (SIDS), three other leading causes of sudden, unexpected infant deaths (SUIDs), and cause unknown/unspecified (top) and infant mortality rates due to SIDS, SUIDs and cause unknown/unspecified (bottom), United States, 1989–2001. The mortality rates are graphed on a log scale at the top. SUIDs include accidental suffocation and strangulation in bed; other accidental suffocation and strangulation; and neglect, abandonment, and other maltreatment syndromes. Data in both graphs are calculated from a US period “Linked Birth/Infant Death Data Set” (10). No linked data files are available for the years 1992–1994.

identical, peaking in the colder months from November through March. However, in 1999–2001, the SIDS and cause unknown/unspecified distributions no longer followed a similar pattern. In this later time period, SIDS had a higher percentage of deaths during January through June compared with cause unknown/unspecified. Conversely, cause unknown/unspecified had a higher percentage of deaths during August

through December with the percentage increasing each month until the end of the year.

#### Risk factors

Maternal sociodemographic risk factors for SIDS remained unchanged for all time periods, but they were



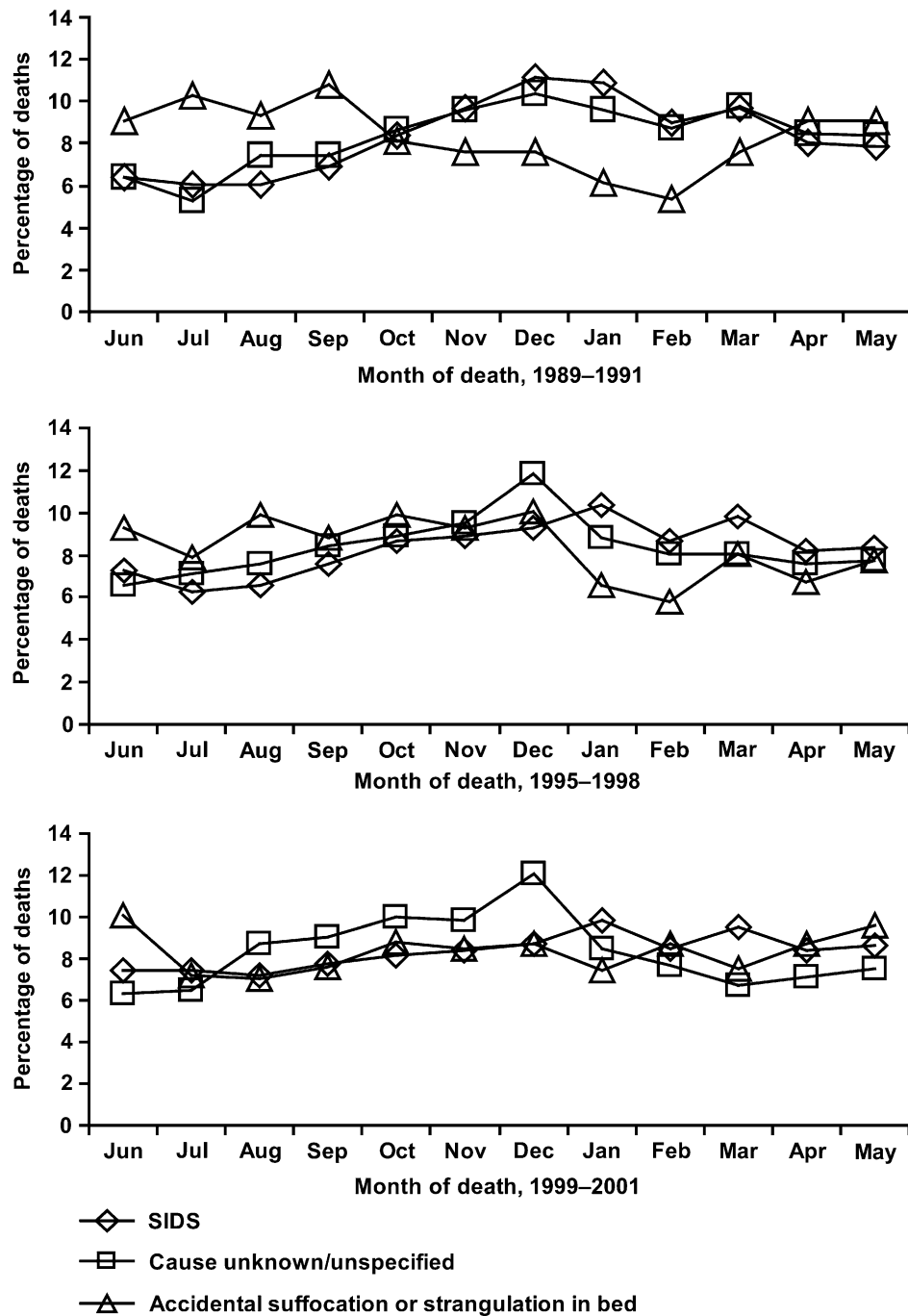
**FIGURE 2.** Percentage distribution of age at death for selected causes of death, United States, 1989–1991, 1995–1998, and 1999–2001. SIDS, sudden infant death syndrome. Data are calculated from a US period “Linked Birth/Infant Death Data Set” (10).

neither sensitive nor specific to SIDS (data not shown). For example, regardless of the cause of SUID, the highest death rates were found among infants with mothers who were aged less than 20 years, were non-Hispanic Blacks and American Indians/Alaska Natives, had low educational levels, were unmarried, were multiparous, and lacked prenatal care. In addition, for each cause of SUID, the infants who were low birth weight (<2,500 g), born preterm (<37

weeks’ gestation), male, and from multiple gestations conferred the highest mortality rates.

## DISCUSSION

Recent reports have highlighted a genuine decline in US SIDS rates attributed to the release of the American



**FIGURE 3.** Percentage distribution of month of death for selected causes of death, United States, 1989–1991, 1995–1998, and 1999–2001. Months are abbreviated according to the first three letters of the full name (e.g., Jun, June). SIDS, sudden infant death syndrome. Data are calculated from a US period “Linked Birth/Infant Death Data Set” (10).

Academy of Pediatrics’ recommendation in 1992 (2) and the initiation of the Back-to-Sleep campaign in 1994 (8, 17). This study shows that the more recent decline in reported SIDS rates from 1999 to 2001 was likely not a true decline but related to changes in the way that these infant deaths are being reported and classified. Factors that

provide evidence of a change in reporting or classification include the following: 1) the recent increase in deaths reported as cause unknown/unspecified in the latter months of the year coupled with a decline in SIDS during these months; 2) the almost doubling of ASSB rates since 1995–1998; 3) the failure to resolve pending cause-of-death



records; 4) the ASSB age of death distribution's becoming more similar to that of SIDS in recent years; and 5) the similar and unchanged epidemiologic profile of SIDS, ASSB, and cause unknown/unspecified between 1989 and 2001 (with the exception of the age and month of death). In addition, the percentage of US infants placed prone to sleep has not changed dramatically since 1999, further supporting our findings that the recent decline in SIDS is not true decline (18).

Our finding that the decline in SIDS in recent years is offset by increasing rates of cause unknown/unspecified and ASSB is consistent with the recently published findings of Malloy and MacDorman (5) regarding SIDS and postneonatal mortality. However, because our study used nationally linked birth and death certificates, we were able to assess patterns in the epidemiologic profile of SIDS, as well as other SUIDs and cause unknown/unspecified.

The issue of unresolved, pending cause-of-death records is important to consider when analyzing SIDS mortality, because death certificates for SIDS cases are likely to be filed as pending cause of death until an investigation is done. Delays in transmitting amendments to the National Center for Health Statistics in these circumstances would likely result in fewer SIDS records and more cause unknown/unspecified records in the national mortality file. The end-of-the-year increase in cause unknown/unspecified records may be explained by unresolved pending records being assigned to cause unknown/unspecified in the national data files when the files are closed.

To confirm this, we compared the number of SIDS and cause unknown/unspecified records reported to the National Center for Health Statistics with the final number of records recorded in the death records for selected states and found evidence of substantial underreporting of SIDS and overreporting of cause unknown/unspecified in the national mortality file. For example, in 2000, California reported 172 SIDS and 210 cause unknown/unspecified records to the National Center for Health Statistics, whereas the final California state vital records showed 222 and 113 records, respectively (19). In 2001, California reported 94 SIDS and 339 cause unknown/unspecified cases to the National Center for Health Statistics, whereas 197 and 123 cases, respectively, were reported in the California vital records (20). The discrepancy between the number of SIDS cases in the state and national mortality files has important implications for analyzing and explaining the decline in SIDS rates and suggests that the national decline between 1999 and 2001 is, at least in part, an artifact. If these cases from California alone were included in the national files, the 2001 US SIDS rate would increase to 59.6 per 100,000 livebirths, a 4.4 percent change in rate, and the cause unknown/unspecified rate would decline to 21.5 per 100,000 livebirths, a 20.1 percent decline. New procedures for transmitting amendments were recently implemented to address this problem, resulting in a substantial decline in unresolved pending records for data year 2002, and should result in further declines in subsequent years.

Another reason for the increase in cause unknown/unspecified cases in recent years may have been a growing reluctance of death certifiers to assign SIDS as the cause of

death unless a thorough investigation had been conducted. Investigators may have been influenced by highly publicized cases wherein SIDS was later found to be homicide (21). In addition, after the Centers for Disease Control and Prevention released *Guidelines for Death Scene Investigation of Sudden, Unexplained Infant Deaths*, including investigation report form 3.96, in 1996 (22), many states either adopted these guidelines and report form or created similar state forms. Use of the Centers' guidelines and investigation report form or these other forms may have led to improved quality of data collection at the death scene and more thoughtful assignment of cause of death. Anecdotally, we have heard that some jurisdictions have limited funding at the end of the year, which on occasion results in less comprehensive death scene investigations being conducted.

Improved and more thorough death scene investigations may also help to explain the steady increase in ASSB rates and the decline in reported SIDS as investigators are more aware of what constitutes an unsafe sleep environment, including the risk associated with soft sleep surfaces and loose bedding (23–27). When an infant is found lying on soft bedding face down, investigators may report the death as an ASSB instead of SIDS.

Finally, the increasingly similar age at death distributions among SIDS, cause unknown/unspecified, and ASSB cases in recent years provide additional evidence that there was a change in the reporting or the classification of SIDS. The age distribution of SIDS cases in infants 2–4-months of age declined in recent years, while deaths attributed to cause unknown/unspecified and ASSB increased in this same age group. The age distribution of the ASSB deaths started changing between 1989–1991 and 1995–1998, while the age distribution for cause unknown/unspecified did not start changing prior to 1995–1998. The change in the distribution for ASSB in the earlier years may provide evidence that the change in reporting or classification began in the earlier time period, but because the rates of ASSB are so small, it had no important effect on the SIDS rate that was dropping during this time.

Although the linked birth/infant death files are the best source of national data, potentially modifiable risk factors for SIDS and other SUIDs, such as sleep position and sleep environment at the time of death, are not within the scope of the vital statistics system. Additionally, data about the quality of the death scene investigation or if an autopsy was performed were not available in the death certificate data for the study years. Collecting this information as part of the death scene investigation would enhance the analysis of trends in SIDS and the identification of preventable risk factors. The Centers for Disease Control and Prevention is exploring the feasibility of a national surveillance system for SUIDs that would collect such data.

This study offers further evidence that much of the decrease in SIDS rates since 1999 may not be a true decline but may be explained by a shift in diagnosis such that cases once reported as SIDS are now reported as ASSB or unknown/unspecified. This shift may be due to changes in the way those investigating infant deaths and certifying the cause of death investigate, diagnose, or report these deaths. The Centers for Disease Control and Prevention initiated the Sudden,

Unexplained Infant Death Initiative in 2004. In late 2005, this initiative began to offer training to those who investigate infant deaths and certify cause of death. The aims of the initiative are to standardize data collection at infant death scenes and to improve the reporting of cause of death on death certificates. Accurate and consistent vital statistics data will allow researchers to monitor trends in SIDS and other SUIDs and to conduct meaningful research, so that new risk factors for SIDS can be identified that will ultimately lead to activities aimed at prevention.

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