 ORIGINAL ARTICLES

Using Death Certificates to Characterize Sudden Infant Death Syndrome (SIDS): Opportunities and Limitations

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Objective To examine cause-of-death terminology written on death certificates for sudden infant death syndrome (SIDS) and to determine the adequacy of this text data in more fully describing circumstances potentially contributing to SIDS deaths.

Study design With 2003 and 2004 US mortality files, we analyzed all deaths that were assigned the underlying cause-of-death code for SIDS (R95). With the terminology written on the death certificates, we grouped cases into SIDS-related cause-of-death subcategories and then assessed the percentage of cases in each subcategory with contributory or possibly causal factors described on the certificate.

Results Of the 4408 SIDS-coded deaths, we subcategorized 67.2% as "SIDS" and 11.0% as "sudden unexplained (or unexpected) infant death." The terms "probable SIDS" (2.8%) and "consistent with SIDS" (4.6%) were found less frequently. Of those death certificates that described additional factors, "bedsharing or unsafe sleep environment" was mentioned approximately 80% of the time. Most records (79.4%) did not mention any additional factors.

Conclusion Our death certificate analysis of the cause-of-death terminology provided a unique opportunity to more accurately characterize SIDS-coded deaths. However, the death certificate was still limited in its ability to more fully describe the circumstances leading to SIDS death, indicating the need for a more comprehensive source of SIDS data, such as a case registry. *(J Pediatr 2009;■:■-■)*.

See related article, p ■

Sudden infant death syndrome (SIDS), first defined in 1969, is now defined as "the sudden death of an infant <1 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."[1] Since 1973, when SIDS was first assigned an International Classification of Diseases (ICD) code, US trends in SIDS have been monitored by counting deaths of infants whose death certificates indicated that SIDS was the underlying cause of the death.[2-4] Although the infant mortality rate attributable to SIDS has declined by >50% since recommendations for supine sleep position were established in the early 1990s, SIDS was still coded as the cause of nearly 2300 infant deaths in 2004.[5,6]

Trends in SIDS rates since the late 1990s are difficult to interpret because of the wide variation in what defines a thorough case investigation, the quality of those investigations, and the comprehensiveness of the reported information.[7,8] Because SIDS and suffocation deaths cannot always be distinguished from one another with autopsy results alone, diagnosis often requires comprehensive evidence from a death scene investigation.[9] The underlying cause-of-death code in the ICD, 10th revision (ICD-10) that the National Center for Health Statistics (NCHS) generates depends on what the medical examiner, coroner, or other certifier reports on the death certificate, and there is substantial variation in how certifiers interpret and adhere to cause-of-death definitions.[10,11] In addition, there is complexity in the computer algorithms in the NCHS Mortality Medical Data System (an automated coding system). In brief, on the basis of ICD-10 coding rules, algorithms are applied to text reported on death certificates and used to code and generate an underlying cause of death. These coding rules were established to improve the usefulness and consistency of mortality statistics by giving preference to certain categories of death, by consolidating conditions, and by systematically selecting a single underlying cause from a reported sequence of conditions.[12] The rules are also used to select an underlying cause in cases in which the certifier has not appropriately specified the underlying cause. For example, in cases in which SIDS is reported as caused by another condition or in which SIDS and another condition are reported on the same line, SIDS can be selected as the underlying cause even

ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th revision
NCHS	National Center for Health Statistics
SIDS	Sudden infant death syndrome
SUID	Sudden unexplained (or unexpected) infant death

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when other better-defined conditions (eg, accidental suffocation in bed) are listed. Risk factors such as bed-sharing are not coded because they are not recognized as causes of death.

A broad range of terms result in a death being assigned the ICD-10 code for SIDS (R95; Table I). Because certifiers are generally unaware of the coding rules and inclusion terms and do not necessarily understand how they are applied, there can be confusion and incongruence between the certifier's intended underlying cause and the actual underlying cause assigned by NCHS. For example, some may view sudden unexplained (or unexpected) infant death (SUID) and SIDS as synonymous.

SIDS is, by definition, nonspecific and therefore is prone to discrepancies in classification. The resulting lack of clarity and reliability are well-documented issues affecting the ability to monitor and understand SIDS trends.[6,8,9] Perhaps more important, the lack of a discernable cause of death limits the ability to identify potentially modifiable risk factors associated with these deaths. SIDS is not a cause of death per se, but a diagnosis of exclusion. The difficulty in accurately classifying these deaths reflects the limitations of investigation, documentation, and our knowledge of the causes of infant mortality.

Beginning in 2003, NCHS electronically captured all text reported by certifiers in the cause-of-death section of all US death certificates. The objective of this study was to examine the actual cause-of-death terminology written on SIDS death certificates and determine the adequacy of these text data to describe more fully the circumstances that may contribute to SIDS. Examination of this text may provide broader and more detailed information about the circumstances and factors associated with SIDS deaths and help us better understand the various terminologies used by certifiers to characterize these deaths.[10]

Table I. List of sudden infant death syndrome-related terms reported by death certifiers resulting in an International Classification of Diseases, 10th revision code of R95 in the National Center for Health Statistics mortality files

Terms
Cot death
Crib death
Sudden death in infancy or SDII
Sudden infant death or SID
Sudden infant death syndrome or SIDS
Sudden unexplained death or SUD
Sudden unexplained (or unexpected) death in infancy or SUDI
Sudden unexplained infant death or SUID
Sudden plus (unexpected) or (unattended) or (unexplained)
Death plus (cause unknown) or (in infancy) or (syndrome)
Infant death plus (syndrome)
Presumed SIDS
Probable SIDS
Consistent with SIDS

Parenthesis signify that the term is used with the preceding term.

Methods

Because the data for this analysis was from a secondary data source, NCHS mortality files, a publicly available data source with no personal identifiers, the study was exempt from ethics committee approval. By using 2003 and 2004 US NCHS mortality files, we selected all deaths assigned the ICD-10 underlying cause-of-death code for SIDS (R95). For each of these deaths, we examined several lines of text from the death certificate's cause-of-death section: 1) part I, which lists the chain of diseases, injuries, or complications that directly caused the death, from the immediate cause to the certifier's statement of the underlying cause; 2) part II, which lists significant conditions contributing to the death besides the underlying cause given in part I; and 3) a line for reporting a description of how an injury, when applicable, occurred (Figure). Although SIDS is not considered to be injury-related, we also examined text from the injury line, because some medical examiners and coroners have been encouraged to use the line to report risk factors or other external conditions associated with the death.[10] Information from these 3 parts were examined without noting the order of appearance.

Next we used a multi-step process to subcategorize all SIDS-coded deaths. First, we grouped together deaths described with the same terminology, and on the basis of these groupings, we divided the SIDS-coded deaths into these SIDS-related cause-of-death subcategories: SIDS; probable SIDS; consistent with SIDS; SUID; sudden infant death; near or atypical SIDS; pending; unknown/uncertain; and miscellaneous.

We also grouped records that contained terms describing contributory or potential causal factors that may have been present, but that are not cause-of-death terms. Such factors included terms indicating co-morbidities, risk factors, and environmental stressors. We excluded non-contributory or non-informative terms (eg, terminal events, nonspecific conditions, and inconclusive pathological findings).

We then created rules for assigning the SIDS-related cause-of-death terms to guide our process and make consistent decisions. For example, when "SIDS" or the word "syndrome" was listed anywhere on a death certificate, we assigned the death to the "SIDS" category; the term "sudden infant death" without the word "syndrome," was given its own category. When text implied uncertainty in the cause of death (eg, SIDS versus suffocation), we assigned the death to the "unknown/uncertain" category.

We also categorized terms related to contributory factors or potential causes of death as: (1) bedsharing or unsafe sleep environment (risky sleep position; sleeping on a sofa or couch); (2) substance abuse (tobacco, alcohol, or illicit drug use); (3) history of recent immunizations; (4) co-morbidities (prematurity; infection, or febrile condition; congenital disorder; apnea; reflux; respiratory, cardiovascular, or liver conditions); (5) suffocation (asphyxiation,

To Be Completed By: MEDICAL CERTIFIER

CAUSE OF DEATH (See instructions and examples)

32. PART I. Enter the chain of events--diseases, injuries, or complications--that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary.

1

Approximate interval: Onset to death

IMMEDIATE CAUSE (Final disease or condition --------> resulting in death) a. ______

Due to (or as a consequence of):

Sequentially list conditions, if any, leading to the cause listed on line a. Enter the UNDERLYING CAUSE (disease or injury that initiated the events resulting in death) LAST

b. ______

Due to (or as a consequence of):

c. ______

Due to (or as a consequence of):

d. ______

PART II. Enter other significant conditions contributing to death but not resulting in the underlying cause given in PART I

2

33. WAS AN AUTOPSY PERFORMED? □ Yes □ No

34. WERE AUTOPSY FINDINGS AVAILABLE TO COMPLETE THE CAUSE OF DEATH? □ Yes □ No

35. DID TOBACCO USE CONTRIBUTE TO DEATH? □ Yes □ Probably □ No □ Unknown

36. IF FEMALE: □ Not pregnant within past year □ Pregnant at time of death □ Not pregnant, but pregnant within 42 days of death □ Not pregnant, but pregnant 43 days to 1 year before death □ Unknown if pregnant within the past year

37. MANNER OF DEATH □ Natural □ Homicide □ Accident □ Pending Investigation □ Suicide □ Could not be determined

38. DATE OF INJURY (Mo/Day/Yr) (Spell Month)

39. TIME OF INJURY

40. PLACE OF INJURY (e.g., Decedent's home; construction site; restaurant; wooded area)

41. INJURY AT WORK? □ Yes □ No

42. LOCATION OF INJURY: State: City or Town:

Street & Number: Apartment No.: Zip Code:

43. DESCRIBE HOW INJURY OCCURRED:

3

44. IF TRANSPORTATION INJURY, SPECIFY: □ Driver/Operator □ Passenger □ Pedestrian □ Other (Specify)

Figure. Portion of the US Standard Certificate of Death in which cause of death is reported, and the three sections from which text data was examined. **1,** Part I of the cause-of-death section, which consists of 4 lines listing the diseases, injuries, or complications that directly caused the death as a chain of events, from the immediate cause on line 1 to the underlying cause (the cause that initiated the events resulting in death) on the last used line. **2,** Part II, a line for entering other significant conditions contributing to the death, but not part of the chain of events described in Part I. **3,** A line for recording a description of how an injury, when applicable, occurred.

aspiration, overlay, entrapment); (6) injury (head injury, fall); and (7) poisoning.

Results

In 2003 and 2004, records of 4408 infant deaths had a SIDS-coded underlying cause of death, and all these records except 20 included some text data that was informative and could be assessed. We subcategorized most of these deaths as "SIDS" (67.3%) and "SUID" (11.0%; Table II). "Probable SIDS" (2.8%) and "consistent with SIDS" (4.6%) were less frequently populated SIDS-related subcategories.

Most records (79.4%) did not mention additional terms describing contributory or possible causal factors (Table II). The proportion of death certificates with >1 contributory or possible causal factor varied with the certainty of the "SIDS-related" subcategory. For example, only 4.6% of the records subcategorized as "SIDS" contained a term describing contributory or possibly causal factors, whereas 19.5% of deaths subcategorized as "probable SIDS" and approximately half the deaths subcategorized as "SUID," "sudden infant death," or "unknown/uncertain" contained at least one other term describing contributory or possible causal factors.

Twelve records subcategorized as "miscellaneous" contained terms such as "not SIDS," "suffocation," or "drug intoxication" (Table II).

The results of the evaluation of autopsy status, manner of death, and age at death in infants whose deaths were coded as SIDS are presented in Table III. Although most death certificates (88.3%) indicated that an autopsy had been performed, only 65.3% indicated that autopsy findings were available before certification. Autopsies were performed and available more often in cases with death certificates subcategorized as "SIDS" than in cases with certificates of all other SIDS-related subcategories. In the evaluation of manner of death, natural manner was reported on 84.6% of certificates we subcategorized as "SIDS," but on only 32.5% of certificates we subcategorized as "other than SIDS" (Table III). In contrast, the manner of death could not be determined on 4.5% of the records for "SIDS" and 32.4% of the records for the "other than SIDS" subcategory. However, 10.2% and 12.6% of the records were missing information on manner of death. Finally, the evaluation of age at death showed that neonatal death was less frequently reported for "SIDS" cases compared with cases in the "other than SIDS" category, 7.0% versus 13.4%, respectively.

Table II. Subcategories assigned to 4408 infant deaths in which SIDS was coded as the underlying cause of death, by whether the death certificate included additional terms describing contributory or possible causal factors, United States, 2003 to 2004

SIDS-related subcategories	Total (n = 4408)	No additional terms describing contributory or possible causal factors (n = 3501)	Additional terms describing contributory or possible causal factors were included (n = 907)
SIDS	2968 (67.3%)	2830 (95.4%)	138 (4.6%)*
Probable SIDS	123 (2.8%)	99 (80.5%)	24 (19.5%)†
Consistent with SIDS	201 (4.6%)	140 (69.7%)	61 (30.3%)
SUID	485 (11.0%)	271 (55.9%)	214 (44.1%)‡
SID	120 (2.7%)	57 (47.5%)	63 (52.5%)
Unknown/uncertain	103 (2.3%)§	48 (46.6%)	55 (53.4%)¶
Near/atypical SIDS	14 (0.3%)	13 (92.9%)	1 (7.1%)
Miscellaneous**	12 (1.2%)	10 (83.3%)	2 (16.7%)
Not meaningful††	382 (8.7%)	33 (8.6%)	349 (91.4%)‡‡

*Includes 6 certificates with pending further investigation terminology.
†Includes 7 certificates with pending further investigation terminology.
‡Includes 2 certificates with pending further investigation terminology.
§Includes 7 certificates in which deaths were reported as caused by either SIDS or suffocation and 1 in which the death was reported as caused by either an inborn error of metabolism or infection.
¶Includes 1 certificate with pending further investigation terminology and 4 with the term "sudden infant death."
**Includes 5 certificates with "not SIDS," 2 with suffocation, 1 with drug intoxication, and 1 with history of recent immunization.
††Includes 349 certificates with pending further investigation terminology and 33 certificates with terminal events, missing information, and miscodes.
‡‡All certificates with pending further investigation terminology.

Of the death certificates that included a description of contributory or potentially causal factors, "bedsharing or unsafe sleep environment" was mentioned on at least 80% of certificates categorized as "consistent with SIDS," "SUID," or "unknown." "Co-morbidities" was the next most commonly mentioned factor on certificates for SIDS-related deaths (Table IV). Other potentially explainable causes of death such as suffocation (n = 10), drug intoxication (n = 6), and injury (n = 6) were reported less frequently (data not shown).

Discussion

Our examination of the actual text data reported by certifiers on 2003 and 2004 death certificates demonstrated that a range of terminology resulted in infant deaths being coded as SIDS (ie, ICD-10 code R95) and that these data are limited in their ability to more fully describe the circumstances and events that contribute to SIDS deaths. Most SIDS-coded deaths (approximately 80%) lacked additional information about contributory or possible causal factors, and thus we could not quantify and describe SIDS deaths that may have been affected by modifiable risk factors such as prone sleeping, soft bedding in the sleep environment, and bed-sharing. It seems likely that certifiers may only report unsafe sleep environment factors on the death certificate when they thought these factors contributed to the death and were less likely to report these factors when they felt that unsafe sleep practices were not involved.

In addition, in our examination of the text data, we found a wide range of terminology used to describe deaths ultimately coded as SIDS (ie, ICD-10 code R95). Although we subcategorized most of these deaths as "SIDS," meaning that the certifier explicitly reported the death as SIDS without any qualifying terminology, nearly one-third of the deaths coded as SIDS were not explicitly reported as "SIDS" by the certifier. The variety of cause-of-death terminology

Table III. Autopsy status, manner of death, and age at death in infants whose deaths were coded "R95" (SIDS), by SIDS related category ("SIDS" versus "Other than SIDS" terminology) in death certificate text, United States, 2003 to 2004

	SIDS-related category, n(%)		
	Total (n = 4408)	SIDS (n = 2968)	Other than "SIDS" (n = 1440)
Autopsy performed	3894 (88.3)	2742 (92.4)	1152 (80.0)
Autopsy finding available to complete cause of death	2880 (65.3)	2103 (70.9)	777 (53.9)
Manner of death			
Natural	2979 (67.6)	2511 (84.6)	468 (32.5)
Accident	13 (0.3)	2 (0.1)	11 (0.8)
Homicide	1 (0.0)	0 (0.0)	1 (0.0)
Pending investigation	329 (7.5)	19 (0.6)	310 (21.5)
Could not be determined	600 (13.6)	132 (4.5)	468 (32.4)
Missing	486 (11.0)	304 (10.2)	182 (12.6)
Age at death			
<28 days	400 (9.1)	207 (7.0)	193 (13.4)
28 days-6 months	3765 (85.4)	2599 (87.6)	1166 (81.0)
7-11 months	243 (5.5)	162 (5.5)	81 (5.6)

Table IV. Percentage of SIDS related cause-of-death subcategories which included descriptive text that had 1 of the 2 most commonly mentioned contributory or possible causal factors: "bed-sharing or unsafe sleep environment" or "co-morbidity," by sudden infant death syndrome-related category, United States, 2003 to 2004

SIDS-related category	Bed-sharing or unsafe sleep environment	Co-morbidity
SIDS	43.5% (60/138)	50.0% (69/138)
Probable SIDS	45.8% (11/24)	41.7% (10/24)
Consistent with SIDS	90.2% (55/61)	27.9% (17/61)
SUID	80.4% (172/214)	30.0% (47/214)
SID	60.3% (38/63)	34.9% (22/63)
Unknown	94.5% (52/55)	1.8% (1/55)

Death certificates could describe >1 additional contributory or possible causal factors.

used by death certifiers in describing these SIDS-coded cases, especially with other descriptive text noting contributory or perhaps other causal factors, reflect an inconsistency in the reporting standards used by death certifiers. Moreover, we found that the text did not contain sufficiently detailed information to know with certainty whether certifiers who did not explicitly report deaths as being caused by SIDS actually intended that these deaths be coded as SIDS. Some certifiers may have wanted to avoid explicitly using the term "SIDS" because of uncertainty about the appropriateness of a SIDS diagnosis. The variety of cause-of-death terminology used by certifiers also may indicate inconsistency in how medical and forensic communities in different states and jurisdictions describe and classify infant deaths.[10-15] However, we did not find clear state-to-state variation in the use of terms describing infant deaths eventually coded as SIDS, although certifiers in New Mexico and New York (excluding New York City) reported the term "SIDS" exclusively (data not shown).

Our results also showed that many SIDS-coded cases are classified without evidence of having had an autopsy before death certification. This may indicate either that case investigations were never completed or that amended death certificates incorporating autopsy findings were not sent to NCHS in time to be reflected in national mortality data.

Although in the case of SIDS, NCHS does not use the manner of death designation in assigning an underlying cause of death code, medical examiners and coroners are instructed to classify SIDS deaths as either natural or undetermined manner of death.[10] In addition, a few states have rules requiring that deaths explicitly diagnosed as SIDS have the manner of death designated as natural. In our study, SIDS was classified as either natural or undetermined manner of death most of the time. For both "SIDS" and "other than SIDS" determinations, <1% of these deaths were reported as accidents and homicides as their manner of death. Age differences between deaths classified as "SIDS" and "other than SIDS" might reflect differences in the way medical examiners and coroners define SIDS. Although by definition, SIDS can occur in any infants <1 year of age, typically SIDS is portrayed as a cause of death occurring in the post-neonatal period.[8]

We found that the degree of specificity or certainty in our sub-categorization of deaths was negatively associated with the presence of terminology indicating the involvement of other factors in the death. For example, of those certificates mentioning additional factors, "bed-sharing or unsafe sleep environment" was noted most often for deaths we subcategorized as "SUID," "consistent with SIDS," or "unknown/uncertain," suggesting greater uncertainty of an actual SIDS diagnosis and the potential of a sleep-related suffocation death. However, the extent of any investigation on which the inclusion of these possible contributing factors was based could not be determined from the text data reported. It seems likely that those deaths listed as "pending" might be those in which certifiers had not completed a more extensive investigation before certifying the death. Finally, although infrequent, we found some cause-of-death misclassification generated by errors in the NCHS computer algorithms, including the misclassification of 5 deaths for which death certificates clearly stated "not SIDS."

The heterogeneity of death certifiers and jurisdictional variations in SIDS reporting practices makes establishing uniformity in the classification and reporting of SIDS particularly challenging. To improve the quality and thoroughness of data collected at infant death scene investigations, all jurisdictions should consider adopting nationally established guidelines, use standardized investigation forms such as those developed as part of the Center for Disease Control's SUID Initiative (http://www.cdc.gov/SIDS/SUID.htm), and train their personnel in the use of these guidelines and forms. In addition, certifiers need training on how to report the cause of death appropriately on the death certificate.

However, training and standardized protocols will have a limited effect on our understanding of SIDS if we continue to rely on death certificate data alone. A national SUID case registry that links death certificates to death scene investigation and pathology data could be one way to improve our understanding of SIDS and trends in SIDS subcategories.[10,11] Calls for such a SUID case registry date to the 1970s.[9,16] The CDC is now conducting a pilot project in several states that builds on the efforts of child death review local and state programs. Child death reviews currently collect information about the factors and circumstances associated with SIDS and other SUIDs, but often lack the resources to review this information at a population level.

Our study had some limitations. First, we were not able to assess 8.3% of the cases because the cause-of-death determination was "pending" further investigation. These were cases in which further investigation resulted in an updated record in the final NCHS mortality file (hence the R95 code). NCHS is pursuing a more formalized process to capture this additional information more fully in the future. Second, although the use of the injury field to provide more detailed information about environmental stressors or risk factors has been encouraged,[10] use of this field is not consistently practiced and may not be acceptable to all state vital registrars. A final

limitation to this study is that we did not analyze SIDS cases that may have been misclassified as deaths with an underlying cause attributed to accidental suffocation or unknown causes. An assessment of these deaths would have increased our understanding of how terminology choices and reporting practices affect SIDS surveillance results.

Despite these limitations, this study is the first to assess text reported on death certificates with an underlying cause-of-death code of SIDS. ICD-10 rules and NCHS algorithms are generally effective and consistent in grouping various terminologies and assigning appropriate cause-of-death codes. However, SIDS is unique because of the variability in the terminology reported, the uncertainty in whether SIDS is the intended diagnosis, and the complicated coding. We need to better understand the variations in terminology, why different terms are used, and how they might be best classified according to the ICD. Such information could be used to inform future revisions to the ICD, resulting in a more accurate and informative estimate of the burden of SIDS and other causes of sudden, unexpected infant death. ■

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