

Problems in the Use of Death Certificates to Identify Sudden Unexpected Infant Deaths

NOEL S. WEISS, MD, DrPH, DELRAY GREEN, RRA,
and DEAN E. KRUEGER, MS

Dr. Weiss is epidemiologist, Mr. Green is medical codification specialist, and Mr. Krueger is acting director, Office of Health Statistics Analysis, National Center for Health Statistics, Health Services and Mental Health Administration. Tearsheet requests to the Office of Health Statistics Analysis, Room 9A-54, Parklawn Bldg., 5600 Fishers Lane, Rockville, Md. 20852.

IN THE PAST decade concern has grown over the problem of sudden and unexplained infant death (sudden infant death syndrome). There have been an increasing number of publications on the subject, and two international conferences have been held. At least two organizations have been formed, The International Guild for Infant Survival and the National Foundation for Sudden Infant Death. In response to this concern, a Congressional Joint Resolution was introduced which requested "the institution of statistical reporting procedures that will provide a reliable index to the incidence and distribution of sudden infant death syndrome cases throughout the Nation" (1).

The incidence of sudden unexplained infant death has been ascertained for specific areas and specific periods of time, both in the United States and abroad (2-4, among others). In these earlier studies, the usual means of ascertaining cause of death were supplemented with a standardized autopsy or a coroner's review of the suspect deaths. Since such a detailed inquiry is not feasible on a

routine basis, the present study was undertaken to determine to what extent information already on the death certificate could be used to identify sudden infant death.

The emphasis here is on sudden *unexpected* infant death (SUDI). Although this is a broader category than sudden *unexplained* infant death, in the absence of autopsy findings (rarely available on death certificates) the two categories are virtually impossible to separate. Peterson (5) has estimated that the large majority of sudden unexpected infant deaths are also unexplained.

Methods and Results

In 1968, among infants who died between the ages of 28 days and 1 year, the number of deaths and mortality rate for the following four cause of death categories were:

<i>Cause of death (eighth revision, International Classification of Diseases, Adapted, 1965)</i>	<i>Number of deaths</i>	<i>Death rate per 1,000 live births</i>
Sudden death (cause unknown) (795)	621	0.18
Found dead (cause unknown) (796.2)	414	0.12
Died without sign of disease (796.3)	478	0.14
Other unknown and unspecified causes (796.9)	543	0.16
Total (795, 796.2, 796.3, 796.9)	2,056	0.59

These are probably the most specific categories for SUDI; that is, they contain relatively few deaths that were not sudden and unexpected. However, in view of the number of SUDI deaths that were expected to occur on the basis of incidence rates in several earlier special studies (table

1), criteria for SUDI based on these categories alone are not sensitive—they account for but a small part of the deaths that were actually sudden and unexpected. Two of the earlier studies, in northern Ireland and King County, Wash. (2,3), included deaths which occurred during the first month of life, but the exclusion of these deaths only slightly reduces the total. Furthermore, all three studies (2–4) reported the incidence of sudden unexplained death, which is a minimal estimate of the incidence of sudden unexpected death.

In an attempt to devise and test criteria for SUDI that (a) had greater sensitivity yet retained high specificity but also (b) used only information available on death certificates, a sample of the certificates on all 2,954 U.S. infants who died in 1968 at age 3 months were examined in detail. This particular age was chosen since a relatively high percentage of deaths at this age are sudden and unexpected.

The following are two possible reasons for the presumed extra SUDI deaths not being coded to one of the four underlying causes of death mentioned:

1. The cause of death was described as sudden and unexpected on the death certificate, but other information (frequently, minor symptoms or pathological findings) was also given in the cause of death section. According to the international coding rules for selecting the underlying cause of death, any cause (except prematurity, 777) is to be preferred over the causes included in symptoms and ill-defined conditions (780–796). Thus, in most cases in which a death stated by the certifier to be sudden and unexpected (795 or 796) has other findings listed in the cause of death section, the underlying cause will not be coded to 795 or 796. Of the total of 2,954 certificates reviewed,

Table 1. Sudden unexplained infant death rate¹ in three studies, all infants and those 3 months old, and estimated deaths for United States, 1968, based on each study

Study	Sudden unexplained infant death rate		Estimated SUDI deaths, U.S. infants 3 months old, 1968
	All infants	Infants 3 months old	
Northern Ireland (2)	2.31	0.40	1,400
King County, Wash. (3)	2.05	.36	1,260
California (4)	1.55	.29	1,015

¹ Per 1,000 live births.

Table 2. Deaths described as sudden and unexpected but attributed to specific cause, by cause, infants 3 months old, United States, 1968

Cause of death (eighth revision, International Classification of Diseases, Adapted, 1965)	Number of deaths	
	Sudden and unexpected	Total
Diseases of the thymus gland (254) . . .	3	5
Acute nasopharyngitis, acute upper respiratory infection (460, 465) . . .	8	50
Bronchitis, bronchopneumonia (466, 485, 486, 490, 491)	35	695
Acute interstitial pneumonia (484) . .	33	238
Pulmonary edema (514, 519.1)	15	29
Accidental mechanical suffocation (E913)	11	108
All other causes except above and 795, 796.2, 796.3, 796.9	46	1,458

there were 151 such cases. The causes of death to which these 151 probably misclassified SUDI deaths were assigned are shown in table 2. Though many of them were assigned to pneumonia of one type or another, these sudden, unexpected deaths nonetheless comprised only a small minority of the pneumonia deaths. Only for disease of the thymus gland and pulmonary edema were sudden and unexpected deaths in the majority.

In the sample, 371 deaths were coded to categories 795, 796.2, 796.3, and 796.9; these, when added to the 151 coded to other categories, give a total of 522 “probable” SUDI deaths. The number of SUDI deaths that would have been expected, on the basis of the prior studies, to have occurred in the sample is shown in table 1. The 522 “probable” SUDI deaths thus far classified represent only one-half of even the lowest estimate.

2. The infant death was sudden and unexpected but was not, for whatever reason, described as such. This reason probably explains the difference between the 1,015–1,400 SUDI deaths that are believed to have occurred (table 1) and the 522 which have been accounted for.

In an attempt to see if other information on the death certificate would discriminate further SUDI deaths, the following items were analyzed: (a) approximate interval between onset and death, (b) place of death, and (c) type of certifier. For example, those deaths in which there was a short interval between onset and death, which did not occur in a hospital, and which were certified by a person who had not previously attended the infant could tentatively be classified as both sudden and

unexpected no matter what underlying cause was coded. Tables 3-5 summarize the information on these items that was obtained from the certificates.

The approximate interval between onset and death was not specified on 59 percent of the certificates (table 3). Among these certificates, the item was left blank on more than 90 percent and stated to be unknown on the remainder. When recorded, the approximate interval did discriminate between "probable" SUDI deaths and others, as "probable" SUDI deaths had a higher percentage with a short interval and a lower percentage with a long interval. The place of death and type

of certifying physician were recorded far more regularly than approximate interval; these also, to some extent, discriminated "probable" SUDI deaths from the rest, because there were relatively more out-of-hospital and coroner-certified deaths among the "probable" SUDI group. Nonetheless, the discrimination was far from complete. This, combined with the absence of approximate interval information on more than half the certificates, made us abandon attempts to further augment the size of the SUDI group by the use of these items, since the gain in defined deaths would be small (only 126 more, even if every infant death with a

Table 3. Percentage of deaths by approximate interval between onset and death and cause of death, infants 3 months old, United States, 1968

Cause of death	Approximate interval between onset and death				Number of deaths
	<1 hour	≥1 hour	Not specified or unknown	All intervals	
Total.....	6.0	35.0	59.0	100.0	2,954
"Probable" SUDI ¹	10.0	4.6	85.4	100.0	522
All other.....	5.2	41.5	53.3	100.0	2,432

¹ Defined as death which either (a) in "cause" section of certificate was described as sudden and unexpected, regardless of coded underlying cause, or (b) was coded to causes 795, 796.2, 796.3, or 796.9.

Table 4. Percentage of deaths by place of death and cause of death, infants 3 months old, United States, 1968

Cause of death	Place of death					Number of deaths
	Home	Other ¹	Hospital	Not specified	All	
Total.....	31.2	20.3	47.7	0.8	100.0	2,954
"Probable" SUDI ²	49.5	25.1	24.0	1.3	99.9	522
All other.....	27.3	19.2	52.8	.7	100.0	2,432

¹ Includes dead on arrival. ² See footnote table 3.

Table 5. Percentage of deaths by certifier of death and cause of death, infants 3 months old, United States, 1968

Cause of death	Certifier					Number of deaths
	Coroner	Attending physician	Other physician	Unknown	All certifiers	
Total.....	49.3	28.9	18.9	3.0	100.0	2,954
"Probable" SUDI ¹	75.7	4.0	16.3	4.0	100.0	522
All other.....	43.6	34.2	19.4	2.8	100.0	2,432

¹ See footnote table 3.

recorded interval between onset and death of less than 1 hour was classified to SUDI) compared to the loss of specificity.

Discussion

From the way information on infant deaths is currently obtained and processed, it is not possible to identify with a satisfactorily high level of sensitivity and specificity those that are sudden and unexpected. The problem lies partly in the variation among certifiers as to what they consider to be a sudden and unexpected event, and it is aggravated by the way in which causes of death are recorded and summarized. First, the death certificate, by calling for conclusions rather than findings, encourages subjectivity in the assessment of cause of death. This makes it likely that over the next few years more and more infant deaths will be labeled SIDS, SUDI, or an equivalent term on death certificates regardless of the actual trend, now that sudden infant death has gained acceptance as an entity. Second, where the death certificate does call for specific information, such as approximate interval between onset and death, the certifier frequently does not provide it (table 3). Finally, even when the certifier describes a death as sudden and unexpected, that death under the current rules for coding cause of death would possibly not be assigned to the appropriate category (for example, 795, 796.2) if diagnostic terms are also entered on the certificate.

In summary, death certificate information perti-

nent to the question of whether or not an infant death was sudden and unexpected is poorly elicited, incompletely provided, and often inappropriately classified. Changes in any and preferably all of these would add to our knowledge of the occurrence of SUDI, which in turn might provide clues as to its causes. Until such changes take place, a method for routinely identifying SUDI based on place of death and nonspecificity of underlying cause, such as the one suggested by Peterson (5), will probably have to suffice.

REFERENCE

- (1) U.S. Congress, House, Committee on Interstate and Foreign Commerce: Joint resolution relating to sudden infant death syndrome, introduced by Mrs. Grasso. H. J. Res. 1131, 92d Congress, 2d sess., Mar. 27, 1972.
- (2) Froggatt, P.: Epidemiological aspects of the northern Ireland study. *In* Sudden infant death syndrome, edited by A. B. Bergman, J. B. Beckwith, and C. G. Ray. University of Washington Press, Seattle and London, 1970, pp. 32-46.
- (3) Bergman, A. B.: Sudden infant death syndrome in King County, Washington: Epidemiological aspects. *In* Sudden infant death syndrome, edited by A. B. Bergman, J. B. Beckwith, and C. G. Ray. University of Washington Press, Seattle and London, 1970, pp. 47-54.
- (4) Kraus, J. F., and Borhani, N. O.: Post-neonatal sudden unexplained death in California: A cohort study. *Am J Epidemiol* 95:497-510, June 1972.
- (5) Peterson, D. R.: Sudden unexpected deaths in infants: Incidence in two climatically dissimilar metropolitan communities. *Am J Epidemiol* 95:95-98, February 1972.

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Death certificates on all U.S. infants who died at 3 months of age in 1968 were examined to see if sufficient information was available to identify those whose death was sudden and unexpected. Of the 2,954 deaths, 371 were coded for official mortality statistics on underlying cause of death to nonspecific causes implying, or compatible with, sudden unexpected death (ICDA eighth revision, 795, 796.2, 796.3, 796.9). An additional 151 deaths were described on the death certificate as sudden and unexpected, but because of the presence of other information in the cause of death section, they were assigned to various specific causes of death. Based on incidence rates from several earlier studies, it was estimated that there

remained at least several hundred additional sudden unexpected infant deaths coded to other causes. Nonetheless, other items that might have been helpful in identifying these deaths, such as approximate interval between onset and death, place of death, and type of certifier, were either infrequently recorded or not sufficiently discriminating to establish criteria for sudden unexpected death that were both sensitive and specific.

Unless changes are made in the construction of the death certificate, the completeness and accuracy with which it is filled out, or the coding of underlying cause of death, it is unlikely that accurate rates of sudden unexpected infant death will be routinely produced in the United States.