



PAPER

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Differentiating Cause-of-Death Terminology for Deaths Coded as Sudden Infant Death Syndrome, Accidental Suffocation, and Unknown Cause: An Investigation Using US Death Certificates, 2003–2004*

ABSTRACT: We compared written text on infant death certificates for deaths coded as sudden infant death syndrome (R95), unknown cause (R99), and accidental suffocation (W75). Using US mortality files supplemented with the death certifiers' written text for all infant deaths with International Classification of Diseases (ICD)-10 assigned codes R95, R99, and W75, we formed cause-of-death subcategories from common themes identified from the written text. Among all infant deaths in 2003–2004, the underlying cause of death was listed as R99 for 2128 deaths, R95 for 4408 deaths, and W75 for 931 deaths. Among the postneonatal deaths, the differences in subcategories varied between assigned ICD-10 codes: for R99-coded deaths, 45.8% were categorized as "Unknown" and 48.6% as "Pending"; for R95-coded deaths, 67.7% were categorized as "sudden infant death syndrome (SIDS)"; and for W75-coded deaths, 76.4% were categorized as "Suffocation." Examination of the written text on the death certificates demonstrates variability in the assigned ICD-10 codes which could have an important effect on the estimates of SIDS cases in the United States.

KEYWORDS: forensic science, SIDS, accidental suffocation, cause unknown, death certificate, SUID

Annually, about 5000 US infants die suddenly without an obvious or immediately identifiable cause (1). Such cases warrant further investigation by a medical examiner or coroner. Most of these sudden unexpected infant deaths (SUID) are attributed on death certificates to sudden infant death syndrome (SIDS) or unknown cause. Many are also commonly reported as accidental suffocation and strangulation in bed (ASSB), such as suffocation by bed linens or being smothered by a caregiver sharing the same sleep surface (2). These three major causes of SUID can be difficult to distinguish from one another without a thorough examination of the death scene, a review of the infant's clinical history, and an autopsy (3). SUID deaths share certain epidemiological characteristics such as similar age distribution at death with the number of SUID deaths peaking at 1–4 months of age, suggesting some overlap in underlying etiology (4).

SIDS is the third leading cause of infant death in the United States and the leading cause of postneonatal death (deaths to infants 28–364 days old); ASSB is the leading cause of injury-related infant death (2,5,6). As recommendations for supine sleep position were established in the early 1990s, the infant mortality rate attributable to SIDS has declined by more than 50% (from 120.3 per 100,000 live births in 1992 to 54.6 per 100,000 live births in 2004) (7). However, from 1999 through 2001, the decline in deaths attributable to SIDS was offset by an increase in deaths attributable to ASSB and to unknown cause. Since 2002, the reported cause-specific SUID rates have remained fairly constant (2,7).

Each death is assigned an underlying cause of death International Classification of Diseases (ICD) code based on information recorded on the death certificate; ICD codes on death certificates are the primary source for documenting trends in SIDS and other causes of infant death in the United States. The Tenth Revision of the ICD (ICD-10) is currently in use (8); and according to ICD-10 coding rules, SIDS deaths are assigned code R95, ASSB deaths, code W75, and deaths owing to unknown causes, code R99. Deaths registered with a cause of death that is pending investigation and where there are no preliminary findings reported are also coded to R99 if the cause is not adjudicated, amended, and sent to the National Center for Health Statistics (NCHS) prior to closure of the national file at the end of the data collection period. The national file is closed when records for all deaths registered in all states are received by the NCHS and when it has been determined that the

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ICD-10 Cause-of-Death Codes	Terms Reported by Death Certifiers Resulting in ICD-10 Codes, per National Center for Health Statistics (NCHS) Algorithms			
SIDS (R95)	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 sudden unexpected infant deaths (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			
Cause unknown (R99)	Reported as no cause or ill-defined terminology not elsewhere classified			
ASSB (W75)	Asphyxia or asphyxiated or asphyxiation or			
	Strangled or strangulated or strangulation <i>or</i> Suffocated or suffocation			
	<i>plus</i> (bed or crib)			
	plus (airway) or (bronchiole) or (mouth) or (nose)			
	or (other specified) or (respiratory) or (skip) or (throat) or (unspecified)			

TABLE 1—Terminology used by CDC National Center for Health Statistics algorithms and rules to assign ICD-10 cause-of-death codes for underlying cause of death attributable to International Classification of Diseases (ICD)-10 codes R95, R99, and W75, United States, 2003–2004.

SIDS, sudden infant death syndrome; ASSB, accidental suffocation and strangulation in bed.

timely receipt of any additional information is unlikely. ICD coding is typically performed by the NCHS Mortality Medical Data System (MMDS), an automated coding system that applies ICD coding rules; however, coding is performed manually if the terminology is not recognizable by MMDS or the coding rules are too complex for MMDS to handle (for example, text that is coded as W75 usually requires manual intervention) (9). According to the NCHS inclusion criteria, certain key terms are coded to SIDS (R95), Unknown (R99), and ASSB (W75) (Table 1). In general, a broad range of terms are used for assignment to codes R95 and W75; when no cause or an ill-defined terminology not elsewhere classified is reported, the cause of death is coded to R99. Code assignment is based solely on what is reported on the death certificate.

However, because certifiers, usually medical examiners or coroners, use inconsistent practices for diagnosing SUID (10,11) and vary in the level of available information and detail they use to describe the death circumstances, it is unclear how reliably the ICD codes reflect the certifier's intended designation of the underlying cause of death. In this study, we sought to compare and contrast the written text on infant death certificates for deaths coded as SIDS (R95), unknown cause (R99), and ASSB (W75), to assess variations in the way these SUIDs are reported by medical examiners and coroners. We hypothesized that examination of the written text might provide important additional information to explain how these deaths are characterized and coded.

Methods

We used specially prepared US mortality files that link text fields to the statistical file compiled by NCHS for 2003 and 2004 to select infant deaths (<365 days) assigned the ICD-10 underlying cause-of-death codes for unknown cause (R99), SIDS (R95), and ASSB (W75). First for all SUID cases, we described the characteristics of deaths assigned to each of these ICD-10 codes by calculating frequencies and percent distributions by age of death, manner of death, and whether an autopsy was performed. Then, we used text-based descriptions of these infant deaths to assign them to mutually exclusive subcategories. The subcategories were created based on common themes in terminology that we derived from the certifiers' written text in the cause-of-death section (Part I), other significant condition section (Part II), and the injury description section of the death certificate (Fig. 1). We created 10 subcategories based on the definitions described in Table 2 and grouped them by the ICD-10 codes they were originally assigned to examine the differences in the text subcategories between assigned ICD-10 codes. The subcategories were grouped by two coders (with >99% agreement); all discrepancies were resolved by discussing the rationale behind the differences and by incorporating feedback from a third party.

We limited our comparison of text fields to postneonatal deaths (deaths to infants 28-364 days old) because the factors associated with neonatal deaths, which represent 13% (987/7467) of all SUID deaths, are likely to be different than the factors associated with deaths that occur later in infancy. SIDS is rare during the first month of life (12); as shown in Fig. 2, the majority of neonatal SUID deaths are attributed to unknown causes. During the postneonatal period, the proportion of deaths owing to unknown causes and to SIDS is nearly equal. For all postneonatal deaths, we calculated the frequency and percentage of the three most frequently reported SUID ICD-10 codes (R99, R95, and W75) by the subcategories that we created. In addition, because co-sleeping or unsafe sleep environment was often reported not as causes of death, but as possible contributory or causal factors leading to the death, we also calculated how frequently death certificates had written text reports of co-sleeping or unsafe sleep environment.

Results

Among all SUID deaths (neonatal and postnatal) in 2003 and 2004, the underlying cause of death was listed as Unknown (R99) for 2128 infant deaths, SIDS (R95) for 4408 infant deaths, and ASSB (W75) for 931 infant deaths. The manner of death reported on the death certificate for Unknown (R99) deaths was usually "pending" or "could not be determined"; SIDS (R95) deaths were mostly described as "natural" or "could not be determined"; and ASSB (W75) deaths were mainly described as "accidental" (Table 3). Among all neonatal and postneonatal SUID deaths, approximately 80% had an autopsy performed. However, fewer certificates indicated that autopsy findings were used when considering designation of underlying cause of death. Approximately 65% of SIDS (R95) and ASSB (W75) deaths had an autopsy finding available to complete the cause of death, compared to 49% of Unknown (R99) deaths. The findings were similar for postneonatal deaths.

Among postneonatal deaths (n = 6480), the underlying cause-ofdeath codes and text subcategories varied. Among R99-coded Unknown postneonatal deaths, we categorized 45.8% as "unknown" and 48.6% as "pending." The remaining 7.2% of the R99-coded deaths were distributed across a variety of subcategories (Table 2). Among R95-coded SIDS postneonatal deaths, we categorized 67.7% as "SIDS," 19.3% as "other SIDS," and 8.1% as "pending." Among W75-coded ASSB postneonatal deaths, we categorized 76.4% as "suffocation," 1.8% as "other suffocation,"

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	 PART I. Enter the <u>chain of</u> arrest, respiratory arrest, or lines if necessary. 	CAUSE OF <u>f events</u> diseases, injurie r ventricular fibrillation wi	DEATH (See instructions es, or complicationsthat directly cause thout showing the etiology. DO NOT	and examples) sed the death. DO NOT (ABBREVIATE. Enter onl	enter termina ly one cause	al events on a line	such as cardiac e. Add additional	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,	b	· · ·						
	if any, leading to the cause listed on line a. Enter the		Due to (or as a consequence	of):					
	(disease or injury that initiated the events resulting		Due to (or as a consequence	e of):					
	in death) LAST	d					······		
	PART II. Enter other significant of	conditions contributing to	<u>death</u> but not resulting in the underly	ing cause given in PART		2	33. WAS AN AUTOPS □ Yes 34. WERE AUTOPSY	Y PERFOR	MED? AVAILABLE TO
							COMPLETE THE CAU	ISE OF DEA	ATH? 🗆 Yes 🗆 No
ER :	TO DEATH?	RIBUTE 36. IF FEM □ Not pr	ALE: egnant within past year		37. MANN	EROFDI al ⊓H	=ATH		
DIete	Yes Probably Pregnar		t at time of death	□ Accident □ Pending Investigation					
CAL (🗆 No 🗆 Unknown	Not pr	egnant, but pregnant within 42 days	of death	Suicid	de ⊡C	ould not be determined		
To Be MEDI		□ Not pr	egnant, but pregnant 43 days to 1 ye	ar before death					
		🗆 Unkn	own if pregnant within the past year						
	 DATE OF INJURY 39 (Mo/Day/Yr) (Spell Month) 	9. TIME OF INJURY	40. PLACE OF INJURY (e.g., D	ecedent's home; constru	iction site; re	staurant;	wooded area)	41. INJU □ \	RY AT WORK? ∕es □ No
	42. LOCATION OF INJURY: St	tate:	City or Town:						
	Street & Number:			Apartment	No.:		Zip Code:		
	43. DESCRIBE HOW INJURY O	CCURRED:					44. IF TRANSPORT	ATION INJU	RY, SPECIFY:
			2				Driver/Operator Passenger		
			5				□ Pedestrian		
							Other (Specify)		

FIG. 1—The cause-of-death section of the US Standard Certificate of Death, including the three subsections from which text was examined for the present study. Notes: (i) Part I of the cause-of-death section consists of four lines listing the diseases, injuries, or complications that directly caused the death as a chain of events, from the immediate cause on Line A to the underlying cause (the cause that initiated the events resulting in death) on the last used of the four lines. (ii) Part II provides a blank space for entering significant conditions contributing to the death that were not a part of the chain of events described in Part I. (iii) This subsection provides a blank space for recording a description of how an injury, if applicable, occurred.

TABLE 2—Subcategories, definitions, and number of occurrences across all three ICD-10 codes (R99, R95, and W75) among postneonatal deaths on the death certificate, 2003–2004.

		ICD-10 Underlying Cause of Death Code, n (%)			
Cause-of-Death Subcategories Based on Themes in Written Text	Definition	Cause Unknown (R99) (<i>n</i> = 1684)	SIDS (R95) (<i>n</i> = 4008)	ASSB (W75) (<i>n</i> = 788)	Combined R99, R95, and W75 (<i>n</i> = 6480)
SIDS	Those deaths where the terminology "SIDS" or "sudden infant death syndrome" or "crib death" was listed alone or as the primary cause of death OR those where the definition of SIDS (after a thorough death scene investigation, complete autopsy, and review of the clinical history, a cause of death was not found) was given.	29 (1.7)	2712 (67.7)	1 (0.1)	2742 (42.3)
Unknown	Those deaths where the terminology "unknown" or "undetermined" was listed with no other cause of death OR those where no known cause of death was listed (i.e., no anatomical, toxicological, or other cause of death).	772 (45.8)	50 (1.2)	2 (0.3)	824 (12.7)
Suffocation	Those deaths where the cause of death was written as caused by asphyxia, overlay, wedging, entrapment, or obstructed airway OR those where the definition of suffocation was written.	1 (0.0)	2 (0.0)	602 (76.4)	605 (9.3)
Other SIDS	Those deaths for which SIDS was not clearly identified as a cause (examples of clear identification include "consistent with SIDS," "near-SIDS," "SID," "SUID"), but that included some variation of SIDS based on the NCHS algorithm.	4 (0.2)	774 (19.3)	1 (0.1)	779 (12.0)
Other suffocation	Those deaths that were not clearly identified as suffocation (examples of clear identification include "consistent with asphyxia") or "near asphyxia"), but included some variation of suffocation, per the NCHS algorithm.	0 (0.0)	0 (0.0)	14 (1.8)	14 (0.002)
Pending	Those deaths where the terminology "pending" or "deferred" was listed anywhere in the cause-of-death section or for R99-coded deaths that had manner of death reported as pending with nothing written in the text field. The term "pending" would precede any other term.	819 (48.6)	326 (8.1)	96 (12.2)	1241 (19.2)

		ICD-10 Underlying Cause of Death Code, n (%)				
Cause-of-Death Subcategories Based on Themes in Written Text	Definition	Cause Unknown (R99) (<i>n</i> = 1684)	SIDS (R95) (<i>n</i> = 4008)	ASSB (W75) (<i>n</i> = 788)	Combined R99, R95, and W75 (<i>n</i> = 6480)	
Two or more causes listed	Those deaths where two or more possible causes were written on the same line (e.g., SIDS and suffocation), except when "unknown cause" (an ill-defined cause) was listed along with a more defined cause. When a more defined cause was written, then the more defined cause was used.	24 (1.4)	10 (0.2)	2 (0.3)	36 (0.01)	
Other listed causes	Those deaths with a known cause of death documented (e.g., limb-body wall syndrome) OR those where the written text cannot be categorized into one of the other categories.	25 (1.5)	7 (0.2)	2 (0.3)	34 (0.01)	
No written text	Those deaths with no written information reported in the cause-of-death section of the death certificate.	9 (0.5)	18 (0.4)	4 (0.5)	31 (0.005)	
Probable	Those deaths that used terms such as "probable" or "possible" or "suspected" or "apparent," reflecting a degree of uncertainty in cause-of-death determination.	1 (0.1)	109 (2.7)	64 (8.1)	174 (2.7)	

TABLE 2—Continued.

SIDS, sudden infant death syndrome; ASSB, accidental suffocation and strangulation in bed.



FIG. 2—Cumulative percentage of sudden infant death syndrome (SIDS) (International Classification of Diseases [ICD]-10 code R95) and cause unknown (ICD-10 code R99) deaths, categorized by age in the neonatal and postneonatal period, 2003–2004.

and 12.2% as "pending." When we combined all R95-, R99-, and W75-coded deaths, we found that 12% were categorized as "other SIDS." Written text reporting co-sleeping or unsafe sleep environment as a possible contributory or causal factor was found in 5.6%, 8.8%, and 75.1% of R99-, R95-, and W75-coded deaths cases, respectively.

Discussion

Examination of the written text on infant death certificates for causes of death coded to R99, R95, and W75 provides some insight into how the characterization and coding of these major causes of SUID may be affected by the terminology used by certifiers. Because of the variability in terminology used on the death certificate and our lack of knowledge regarding the certifier's intended designation for underlying cause of death, we found it difficult to clearly distinguish differences among the deaths that are coded R95, R99, and W75. Notably, we found text regarding co-sleeping or unsafe sleep environment as a possible contributory or risk factor in cases assigned to one of the three SUID codes. However, the frequency of reporting these sleep-related terms

varied; they appeared in the majority of ASSB-related death certificates but only a small minority of other SUID deaths. Because the presence of an unsafe sleep environment is a risk factor for SIDS and a necessary cause for ASSB, and is cited as a factor in many deaths of unknown cause, it is difficult to distinguish the degree to which an unsafe sleep environment contributes to the coding of underlying cause of death as R95-, R99-, and W75-coded deaths without more detailed information. Moreover, death certificate data typically do not have sufficient details about the circumstances surrounding these SUID cases. In addition, when the certifier writes "SUID" or "near-SIDS" as the designation for the underlying cause of death, it might indicate that the certifier purposely did not choose a SIDS designation, perhaps because of lack of sufficient evidence. In this circumstance, an R99 code might more accurately reflect the certifier's intended designation of underlying cause of death. Alternatively, when "SUID" or "no known cause" is written, a SIDS designation could have been potentially met, but the certifier may prefer to use terminology other than "SIDS," in which case an R95 code would best reflect the designation of underlying cause of death.

We found that the majority of deaths were assigned codes that are consistent with the subcategories we created based on the literal text. However, a great deal of variation exists in certification of infant deaths (11). Variation in terms used for death certification will result in some incongruence between the certifier's intended designation of underlying cause of death and the NCHS-assigned cause-of-death code. When we combined R95-, R99-, and W75coded certificates, we found that 12% of death certificates included text-based entries that did not clearly describe SIDS as the cause of death, but instead described some variation in SIDS terminology, such as "SID," "SUID," or "near-SIDS." These variations potentially demonstrate a degree of uncertainty on the part of the certifier as to whether the death should be certified as SIDS (13). However, according to the NCHS inclusion terms, regardless of intent, certain key terms will be coded to SIDS (R95). In some cases, differences may be subtle. For example, the text "unknown cause of death" would be coded to Unknown (R99), whereas the text "unknown sudden death" would be coded to SIDS (R95); the difference is in the use of the term "sudden." Both indicate an unknown cause of death, but the difference in terminology results in the assignment of different ICD codes. In addition, we could not determine whether the Unknown code R99 indicates that the

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TABLE 3—Autopsy performance and manner of death determination for R99-, R95-, and W75-coded deaths, United States, 2003–2004.

	ICD-10 Cause of Death Codes, n (%)			
	Cause Unknown (R99)	SIDS (R95)	ASSB (W75)	
All cases	n = 2128	n = 4408	<i>n</i> = 931	
Autopsy performed	1757 (82.6)	3894 (88.3)	753 (80.9)	
Autopsy finding available to complete cause of death Manner of death*	1051 (49.4)	2880 (65.3)	626 (67.2)	
Natural	196 (9.2)	3225 (73.2)	0 (0)	
Accident	2(0.1)	13 (0.3)	915 (98.3)	
Homicide	2(0.1)	1 (0)	1 (0.1)	
Pending investigation	758 (35.6)	31 (0.7)	1 (0.1)	
Could not be determined	964 (45.3)	700 (15.9)	10 (1.1)	
Missing	206 (9.7)	438 (9.9)	4 (0.4)	
Postneonatal cases (≥28 days)	n = 1684	n = 4008	n = 788	
Autopsy performed	1438 (85.4)	3549 (88.6)	636 (80.7)	
Autopsy finding available to complete cause of death	875 (52)	2635 (65.7)	524 (66.5)	
Manner of death*				
Natural	120 (7.1)	2986 (74.5)	0 (0)	
Accident	2 (0.1)	11 (0.3)	776 (98.5)	
Homicide	1 (0.1)	1 (0)	1 (0.1)	
Pending investigation	618 (36.7)	28 (0.7)	1 (0.1)	
Could not be determined	818 (48.6)	590 (14.7)	8 (1)	
Missing	125 (7.4)	392 (9.8)	2 (0.3)	

*Not all US states use the manner-of-death field.

SIDS, sudden infant death syndrome; ASSB, accidental suffocation and strangulation in bed.

circumstances of the death were not consistent with SIDS (because a complete investigation or autopsy was not conducted), or whether the circumstances were consistent with SIDS, but the certifier chose not to report SIDS for some unidentifiable reason. Therefore, many of the 45.8% deaths coded R99 and described only as "unknown" or "undetermined" could potentially be SIDS or suffocation deaths. However, to more consistently classify these types of deaths, more detailed information describing the circumstances leading to them is needed.

By definition, SIDS should only be diagnosed after a thorough examination of the death scene, a review of the clinical history, and performance of an autopsy fail to find an explanation for the death (3). However, death certificates do not have a field to indicate whether a death scene investigation was completed. A proportion of all SUID cases is not fully investigated and, when they are, investigation data important for establishing cause of death are not collected and reported consistently (14). Death certificates do have fields with checkboxes to indicate whether or not an autopsy was performed and whether the autopsy findings were available to the certifier prior to certifying the cause of death; however, these fields do not collect any information regarding the completeness of the autopsy performed. Neither ICD nor NCHS use the autopsy performance checkboxes as criteria for coding SIDS as an underlying cause of death. Thus, because death certificates provide only limited information on the thoroughness of a case investigation, they are not sufficient for determining whether a SIDS or other unknown cause designation is appropriate (3). These limitations ultimately affect researchers' abilities to accurately monitor national trends, which are particularly important if assessing whether patterns or diagnostic preferences are changing over time.

This analysis has a few limitations. First, for many of the SUID cases examined in this analysis, the completion of medicolegal investigations resulted in amended cause of death statements, which can change the final assigned underlying ICD cause-of-death codes. In some cases, these changes are not reflected in the mortality files containing the written text that we used in our analysis because

when the statistical file is created it does not reflect all changes made after the file is closed. NCHS is currently developing a more systematic process to ensure consistency between the codes and written text in the final statistical file for future years. Second, because coded or written text fields in death certificate data do not provide sufficient insight into the certifier's intended designation of underlying cause of death, we cannot determine if the assigned ICD codes accurately classify what the certifier intended. Finally, the consistency in how the autopsy performance checkboxes are used is unknown and therefore our assessment of reported autopsies based on the death certificate checkboxes is limited.

This population-based study of US infant deaths is the first to compare the written text reported on death certificates for the three most frequently reported SUIDs, namely SIDS, unknown cause, and ASSB. While ICD-10 rules and NCHS algorithms are effective and consistent in assigning underlying cause-of-death codes and fulfill their purpose of being an international standard diagnostic classification for general epidemiology purposes (8), our examination of the written text on these death certificates demonstrates some variability in the codes assigned to the text categories. Minimal information written in the text fields may in part reflect both inconsistent practices (e.g., preferential designations for underlying cause of death) among death certifiers and the complicated coding rules. This can result in misclassified deaths, which can have an important effect on estimates of the number of SIDS cases. CDC nationwide training which emphasized improvements in certification of infant deaths from 2006 and 2008 may potentially improve the way certifiers describe these infant deaths on death certificates. Certifiers receiving such training may use more specific and consistent terminology when describing the deaths. More specific, detailed, and consistent reporting on the part of the certifiers could reduce the variability in terminology used and could allow for changes to the ICD and to the NCHS algorithm that could improve the classification of these ICD-10 codes. In addition, collection of additional death scene investigation and pathology information through a SUID case registry

linked to death certificates could contribute to the development of guidelines for categorizing these deaths more accurately. Improved reporting and classification will enhance our ability to track cause-specific types of SUID and their characteristics over time, which will lead to increased knowledge about potential risk factors that are amenable to prevention.

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