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Half Century Since SIDS: A Reappraisal of Terminology

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AAP TASK FORCE ON SUDDEN INFANT DEATH SYNDROME, COUNCIL ON CHILD ABUSE AND NEGLECT, COUNCIL ON INJURY, VIOLENCE, AND POISON PREVENTION, SECTION ON CHILD DEATH REVIEW AND PREVENTION, NATIONAL ASSOCIATION OF MEDICAL EXAMINERS

After a sudden infant death, parents and caregivers need accurate and open communication about why their infant died. Communicating tragic news about a child's death to families and caregivers is difficult. Shared and consistent terminology is essential for pediatricians, other physicians, and nonphysician clinicians to improve communication with families and among themselves. When families do not have complete information about why their child died, pediatricians will not be able to support them through the process and make appropriate referrals for pediatric specialty and mental health care. Families can only speculate about the cause and may blame themselves or others for the infant's death. The terminology used to describe infant deaths that occur suddenly and unexpectedly includes an assortment of terms that vary across and among pediatrician, other physician, or nonphysician clinician disciplines. Having consistent terminology is critical to improve the understanding of the etiology, pathophysiology, and epidemiology of these deaths and communicate with families. A lack of consistent terminology also makes it difficult to reliably monitor trends in mortality and hampers the ability to develop effective interventions. This report describes the history of sudden infant death terminology and summarizes the debate over the terminology and the resulting diagnostic shift of these deaths. This information is to assist pediatricians, other physicians, and nonphysician clinicians in caring for families during this difficult time. The importance of consistent terminology is outlined, followed by a summary of progress toward consensus. Recommendations for pediatricians, other physicians, and nonphysician clinicians are proposed.

abstract

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BACKGROUND

Tremendous progress has been made since sudden infant death syndrome (SIDS) was first defined in 1969.[1] Substantial reductions in

sudden infant deaths have been largely attributable to the promotion of safe sleeping environments, especially supine sleep position.[2] Yet, every year in the United States, approximately 3500 infants still die suddenly and unexpectedly, and further declines in these deaths have slowed considerably since 1999.[3] Although death-scene evidence and witness accounts may help provide some clues about why and how deaths occur, these deaths are often unobserved or unwitnessed events, and the lack of standardized death-scene investigation and autopsy practices means that many remain a mystery.

To determine the cause and manner of a sudden unexpected infant death (SUID), a formal case investigation should be undertaken, examining medical, social, and other factors that might have played a role. Because there is no biological marker to conclusively diagnose suffocation, whether intentional or unintentional, information from the scene investigation, together with witnessed accounts of the events leading to the death, are critical for establishing cause. Without a thorough case investigation, child abuse, unsafe products and environments, and other threats to public health cannot be identified, and effective intervention strategies cannot be implemented.

Ideally, the investigation includes a scene investigation with caregiver and witness interviews, a doll reenactment, documentation and photographs describing the sleep environment and other environmental characteristics, a review of the child's clinical history, and a full postmortem examination and testing.[4–7] Information about the circumstances and events surrounding the death is dependent on the quality and depth of the death-scene investigation and documentation from first responders, law enforcement, medicolegal death investigators, and other health and social service providers. Standardized scene investigation[8] and autopsy protocol[9,10] guidance exists but is not followed universally.[11] In addition, many medical examiner and coroner offices lack sufficient training and resources to conduct thorough, consistent case investigations.[12] Even when sophisticated tools, such as genetic testing, are available, the extent that a neurologic condition or cardiac defect may have contributed to a SUID may not be known.[13–15] It is not often possible to determine if a specific condition or defect caused the death or whether the condition or defect was an unrelated finding.

Consider a common sudden death scenario: a healthy infant is placed to sleep in an adult bed with pillows and blankets, and an exhausted caregiver falls asleep next to the infant. The caregiver awakens hours later and finds the infant unresponsive and unable to be resuscitated. Although the infant was asleep in an unsafe sleep environment, the events leading to the death were unobserved. Evidence to substantiate that the infant was overlaid or the infant's airway had been obstructed by soft bedding is not available. There are no biological markers to differentiate suffocation from a possible natural cause.[4] If the cause of death cannot be determined after a thorough scene investigation, it will be considered a result of indeterminable cause.

What should these deaths be called? How should they be classified? The terminology used to classify these infant deaths varies among US death certifiers (medical examiners and coroners) and includes a variety of terms and acronyms, including undetermined, unexplained, and unknown cause as well as SIDS, SUID, and accidental suffocation or asphyxia in an unsafe sleeping environment.[16,17] This report describes the history of SIDS terminology and summarizes the debate over the terminology and its resulting diagnostic shift. The importance of consistent terminology is outlined, followed by a summary of progress toward consensus. Recommendations for pediatricians, other physicians, and nonphysician clinicians to facilitate consensus are proposed. Because terminology and clinical guidance for brief resolved unexplained events (formerly, apparent life-threatening events) was published by the American Academy of Pediatrics (AAP) in 2016, this subject is not addressed in this report.[18]

HISTORY OF SIDS TERMINOLOGY

SIDS was first coined and defined by Dr Bruce Beckwith in 1969.[1,19] Beckwith defined SIDS as "the sudden death of any infant or young child, which is unexpected by history, and in which a thorough post-mortem examination fails to demonstrate an adequate cause for death"[1] (Table 1). Sudden refers to the fact that death comes without warning, and unexpected means that there was no preexisting condition known that could have reasonably predicted it. When the definition was first introduced, it established a common term, focusing attention on this group of infant deaths, and helped to address the stigma associated with these deaths. The term SIDS and its definition were subsequently adopted internationally,[20,21] allowing researchers and policymakers to establish a scientific research agenda to explore its epidemiology and etiology. However, even with wide acceptance, SIDS remains a diagnosis of exclusion without clearly defined objective criteria. The use of the term SIDS and how it

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TABLE 1 Selected Terminology and Definition or Criteria to Classify Unexplained Sudden Deaths in Infants and Accidental Asphyxiation

Terminology	Case Definition
Beckwith, 1969[1]	
Sudden Infant Death Syndrome (SIDS)	"The sudden death of any infant or young child, which is unexpected by history, and in which a thorough post-mortem examination fails to demonstrate an adequate cause for death."
Willinger et al, 1989[6]	
Sudden Infant Death Syndrome (SIDS)	"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."
Undetermined or unexplained cause	"Cases that are autopsied and carefully investigated, but which remain unresolved may be designated as 'undetermined,' 'unexplained,' or the like. 'Unresolved' cases are those for which the history, investigation, or autopsy reveals information that places death outside the SIDS category but does not explain the cause of death. Examples of the latter, are suspected cases of abuse, neglect, or accidental suffocation; cases with episodes of vomiting or diarrhea in 24 hours prior to death without pathologic evidence of infection; or cases in which the information regarding death is not reliable."
Krous et al, 2004[5]	
General definition: Sudden Infant Death Syndrome (SIDS)	"Sudden unexpected death of an infant less than 1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history."
Category IA SIDS: classic features of SIDS present and completely documented	"Infant deaths that meet the requirements of the general definition and also all of the following requirements. Clinical • More than 21 days and <9 months of age. • Normal clinical history, including term pregnancy (gestational age of ≥37 weeks). • Normal growth and development. • No similar deaths among siblings, close genetic relatives (uncles, aunts, or first-degree cousins), or other infants in the custody of the same caregiver. Circumstances of Death • Investigation of the various scenes where incidents leading to death might have occurred and determination that they do not provide an explanation for the death. • Found in a safe sleeping environment, with no evidence of accidental death. Autopsy • Absence of potentially fatal pathologic findings. Minor respiratory system inflammatory infiltrates are acceptable; intrathoracic petechial hemorrhage is a supportive but not obligatory or diagnostic finding. • No evidence of unexplained trauma, abuse, neglect, or unintentional injury. • No evidence of substantial thymic stress effect (thymic weight of <15 g and/or moderate/severe cortical lymphocyte depletion). Occasional 'starry sky' macrophages or minor cortical depletion is acceptable. • Negative results of toxicological, microbiologic, radiologic, vitreous chemistry, and metabolic screening studies."
Category IB SIDS: classic features of SIDS present but incompletely documented	"Infant deaths that meet the requirements of the general definition and also meet all of the criteria for category IA except that investigation of the various scenes where incidents leading to death might have occurred was not performed and/or 1 of the following analyses was not performed: toxicological, microbiologic, radiologic, vitreous chemistry, or metabolic screening studies."
Category II SIDS	"Infant deaths that meet category I criteria except for ≥1 of the following: Clinical • Age range outside that of category IA or IB (ie, 0–21 days or 270 days [9 months] through first birthday). • Similar deaths among siblings, close relatives, or other infants in the custody of the same caregiver that are not considered suspect for infanticide or recognized genetic disorders. • Neonatal or perinatal conditions (for example, those resulting from preterm birth) that have resolved by the time of death. Circumstances of Death • Mechanical asphyxia or suffocation caused by overlaying not determined with certainty. Autopsy

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TABLE 1 Continued

Terminology	Case Definition
	• Abnormal growth and development not thought to have contributed to death. • Marked inflammatory changes or abnormalities not sufficient to be unequivocal causes of death."
Unclassified sudden infant death	"Infant deaths that do not meet the criteria for category I or II SIDS but for which alternative diagnoses of natural or unnatural conditions are equivocal, including cases for which autopsies were not performed."
Goldstein et al, 2019[15]	
Unexplained sudden death in infancy or Sudden Infant Death Syndrome	"The sudden unexpected death of an apparently healthy infant under one year of age that remains unexplained after a thorough case investigation, including performance of a complete autopsy with ancillary testing, examination of the death scene, and review of the clinical history." Special note: "Infant deaths with adequate death scene investigation and autopsy, with a history of bed/sleep surface sharing, soft bedding, or non-supine sleep, and without physical evidence of asphyxia, may be more appropriately certified as unexplained sudden death in infancy or sudden infant death syndrome."
Other ill-defined or unspecified causes of death (undetermined)	"The investigation, death scene examination, or autopsy was substantially limited, incomplete or insufficient (eg, legal/religious restrictions, delayed report of death that limits scene investigation, or decomposition)." Or "The investigation, death scene examination, or autopsy had inconsistent accounts or other findings raise competing conclusions about the cause of death."
Unintentional threat to breathing (accidental asphyxia): certification of asphyxia	"Adequate evidence must be documented to substantiate asphyxiation, given the decedent's age and stage of development. There cannot be a reasonable competing cause of death after a complete autopsy with ancillary testing, examination of the death scene (with a doll re-enactment when appropriate), and review of the clinical history. Bed/sleep surface sharing, soft bedding, or prone sleep, without adequate evidence for airway obstruction or chest wall compression, are insufficient to certify a death as due to asphyxia. These deaths may be more appropriately certified as unexplained sudden death or SIDS. The use of 'possible' or 'probable' asphyxia will result in the death being classified as asphyxia."
National Association of Medical Examiners Panel on Sudden Unexpected Death in Pediatrics, 2020[10,14]	
Unexplained sudden death (no identified intrinsic or extrinsic factors)	"Infant less than one year of age in apparent good health that dies suddenly and unexpectedly. • For Sleep-related Deaths: o Placed alone, supine, in infant-specific sleep environment (eg, crib, bassinet, portable crib, play pen) with flat, firm sleep surface, uncluttered by objects, and without potential areas of entrapment. o Found unresponsive or dead, in the same sleep environment, with no obstruction of the nose and/or mouth or compression of neck/chest to cause asphyxia given the developmental abilities of the infant, as described by finder and demonstrated by doll reenactment. • The infant was not overly dressed or bundled for the environmental temperature. • Competent caregiver not impaired by drugs or alcohol. • Physical findings on body and at scene consistent with history provided by caregiver. • Completion of scene investigation and doll reenactment unless caregiver declines. • Review of child medical records and family health history. • Complete autopsy with histology, comprehensive toxicology testing (including vitreous chemistries if possible), and skeletal survey. • No anatomic, metabolic, toxicological, chemical, historical, or external cause of death identified. Genetic testing is recommended but not required for this certification. • No extrinsic or intrinsic risk factors are identified."
Unexplained sudden death (intrinsic factors identified)[a]	• "A cause of death cannot be determined and criteria for Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors) are not met due to o intrinsic/natural abnormalities that are either known risk factors for sudden death (including, but not limited to, low birth weight, preterm birth, small for gestational age, concurrent non-lethal illness, febrile seizures) o or are of unknown significance (including, but not limited, to mutations of unknown significance). • Trauma and other unnatural etiologies are sufficiently excluded."

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TABLE 1 Continued

Terminology	Case Definition
Unexplained sudden death (extrinsic factors identified)[b]	"A cause of death cannot be determined and criteria for Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors) are not met due to the presence of unintentional extrinsic factors that increase risk for unnatural death. This may include, but is not limited to, non-lethal injuries or injuries of unknown significance, nonlethal toxicological findings of unknown significance, or circumstances otherwise concerning for unnatural death."
Unexplained sudden death (intrinsic and extrinsic factors identified)[a,b]	"A cause of death cannot be determined and criteria for Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors) are not met due to a combination of intrinsic and extrinsic factors as described above."
Undetermined (not further specified)	"A cause of death cannot be determined due to circumstances or findings that make the above classifications inapplicable. Examples may include: Inconsistent histories and/or other evidence that raise uncertainty about manner of death, and competing causes of death. Cases which remain undetermined but were not sudden."
Undetermined (insufficient data)	"A cause of death cannot be determined because investigation, death scene examination, or autopsy were substantially limited, incomplete, or insufficient. Examples may include legal/religious restrictions, delayed report of death that limits scene investigation, and/or decomposition."
Asphyxia	"The case must have a complete/full autopsy. Toxicology, histology, vitreous electrolytes, cultures, and review of medical history are to be performed, as necessary as determined by investigation and autopsy. The infant must have obstruction of both nose and mouth or compression of the neck or chest, that is reliably witnessed or demonstrated by doll reenactment, or other reliable evidence of overlay or entrapment. Asphyxiation must be probable given infant's age and stage of development. There cannot be a reasonable competing cause of death."

[a] "Intrinsic factors are: natural conditions or risk factors associated with abnormal physiology or anatomy that are concerning as contributors to death but are insufficient as a cause (eg, low birth weight, preterm birth, small for gestational age, concurrent non-lethal illness, history of febrile seizures), or natural conditions of unknown significance (eg, cardiac channelopathy or seizure gene variants of unknown significance)."

[b] "Extrinsic factors are: conditions in the child's immediate environment that are a potential threat to life but cannot be deemed the cause of death with reasonable certainty (eg, side or prone sleep if unable to roll to supine, over-bundling without documented hyperthermia, objects in immediate sleep environment, sleep environment not specifically designed for infant sleep, soft or excessive bedding, and sleep surface sharing), injuries or toxicologic findings that are either non-lethal or of unknown lethality, or circumstances/findings otherwise concerning for unnatural death."

should be labeled and defined are controversial and complex topics that remain debated.[16,17,19] Many classifications and definitions exist, but none have been accepted universally.[1,5,6,10,15,22–26]

In 1989, 20 years after SIDS was first defined, the National Institutes of Health (NIH) convened a multidisciplinary panel of 12 experts to update the original SIDS definition (Table 1).[6] The panel described SIDS 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" (Table 1). Although similar to the 1969 definition, the revised definition limited SIDS to infants younger than 1 year and required a review of the history and examination of the death scene. The explicit requirement of a scene investigation was in part because of the recognition of the investigation's value in identifying specific causes of death.[6,27] Ultimately, this requirement led to the 1996 creation and adoption of recommended standards on how to conduct a scene investigation for these infants, which included the Centers for Disease Control and Prevention's Sudden Unexplained Infant Death Investigation Reporting Form, investigation guidelines, and national training.[8,28]

In 2004, an international group of SIDS experts met in San Diego, California, to again refine the SIDS definition.[5] The expert group of 10 pediatric pathologists, forensic pathologists, and pediatricians included Dr Beckwith and was led by Dr Henry Krous. The group agreed on a revised general definition and series of subcategory definitions for sudden infant deaths (Table 1).[5] The revised definition, often referred to as the "San Diego definition," characterized SIDS as the "sudden unexpected death of an infant less than 1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history." This revised definition, like previous iterations, emphasized that SIDS was a diagnosis of exclusion. New to the definition was identifying that these

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deaths occurred during sleep. Furthermore, subcategories of sudden infant death were introduced: category IA SIDS (classic features of SIDS present and completely documented); category IB SIDS (classic features of SIDS present but incompletely documented); category II SIDS; and unclassified sudden infant death (Table 1). The unclassified sudden infant death category was intended to capture cases in which "alternative diagnoses of natural or unnatural conditions are equivocal, including cases for which autopsies were not performed." Of note, the 1989 NIH panel had similarly recommended that cases lacking a postmortem examination and that remained "unresolved" after a thorough case investigation be classified as undetermined or unexplained cause and not as SIDS.[6] Examples of unresolved cases were "suspected cases of abuse, neglect, or accidental suffocation; cases with episodes of vomiting or diarrhea in 24 hours before death without pathologic evidence of infection; or cases in which the information regarding death is not reliable."

TERMINOLOGY DEBATE

Even with periodic revisions and updates to the 1969 SIDS definition, vigorous debate continues regarding the labeling and classification of sudden unexplained infant deaths. SIDS is the favored term for many academic and clinical researchers because it was the term used most often in published etiologic and observational risk factor studies during the 1970s–1990s. However, in the US forensic medicine community, many medical examiners and coroners have discontinued using the term SIDS and often use other designations, such as undetermined cause, sudden unexplained infant death, and other terms that reflect a possible accidental suffocation in an unsafe sleep environment.[16] There is also disagreement among US medical examiners and coroners as to whether infant deaths meeting the SIDS definitions could constitute a "syndrome"[4,17]: a term that refers to a disease or condition with a common group of signs and symptoms.[5] These sudden deaths occur in apparently healthy infants with no identified medical conditions or disease; therefore, many argue against the use of the word syndrome.[5,17] Others argue that the term SIDS conveys a certainty of diagnosis, although the underlying cause of SIDS remains unknown.[5,17] Others believe that SIDS is a diagnosis of exclusion, and, although a natural or unnatural cause may or may not exist, the degree of uncertainty precludes a more definitive cause determination.[10,17]

Because there is no universally accepted standard procedure regarding classification of sudden infant deaths, variable terms and acronyms have been used in scientific, practice, and policy documents. Frequently used acronyms and terms include SIDS, SUID, "SUDI," unexplained, unexpected, and undetermined causes. SUID has become an umbrella term to describe sudden infant deaths, including those deaths previously called SIDS.[15,29,30] The "U" in SUID can refer either to unexpected or unexplained. SUID terms are frequently used interchangeably, often without careful reflection as to what the "U" signifies. In the United Kingdom, Europe, Australia, and New Zealand, "SUDI" is often used in place of SUID, referring to sudden unexpected death in infancy or sudden unexplained death in infancy. Most would agree, however, that before investigation, when an immediate cause is not obvious, deaths are both unexpected and unexplained. After investigation, the death is either explained or remains unexplained. Because these deaths commonly occur in an unsafe sleeping environment, they are increasingly referred to as sleep-related infant deaths. The AAP has acknowledged terms other than SIDS, including SUID and sleep-related infant deaths, in their clinical reports "SIDS and Other Sleep-Related Infant Deaths: Evidence Base for Updated 2016 Recommendations for a Safe Infant Sleeping Environment"[2] and "Identifying Child Abuse Fatalities During Infancy."[7]

For the forensic medicine community, evidence at the death scene may point to a possible asphyxiation caused by caregiver overlay or soft bedding, but the unobserved and unwitnessed nature of most of these deaths and lack of conclusive findings indicating a medical condition at autopsy can prevent the death certifier from attributing a specific cause. For example, some cases interpreted as SIDS may be an intentional smothering, but smothering, like drowning and many other asphyxia related conditions, may have no demonstrable findings at autopsy. Given this conundrum, some medical examiners and coroners may prefer to classify infant deaths occurring in an unsafe sleep environment as undetermined cause or possible or probable accidental asphyxiation in an unsafe sleep environment. Some medical examiners and coroners will be comfortable certifying these deaths as accidental suffocation or asphyxiation. Factors contributing to explained suffocation deaths, such as shared sleep surface and soft bedding in the sleep environments, are also risk factors for, but not necessarily causes of, SIDS.[4,31] Classification decisions may be influenced by office policies,[32] personal beliefs and biases,[33]

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previous training,[4] and diagnostic preferences.[16]

DIAGNOSTIC SHIFT

Inconsistent reporting practices, lack of consensus on terminology, and changes in understanding why these deaths occurred have resulted in a diagnostic shift among medical examiners and coroners.[3,34,30] As previously noted, US death certifiers have moved away from reporting SIDS and toward reporting other designations, such as undetermined cause and accidental suffocation and strangulation in bed.[3,16] This diagnostic shift, which has also been observed in other countries such as New Zealand and Australia,[35,36] affects both surveillance and epidemiological and etiologic research. Importantly, for surveillance and research that rely on death certificate data, the diagnostic shift has resulted in variability in attribution of cause, making it difficult to accurately differentiate explained causes (ie, accidental suffocation and strangulation in bed) from unexplained causes (ie, SIDS and other undetermined causes). These explained and unexplained causes share risk factors, but the level of evidence used to determine the cause is inconsistent among death certifiers.[16]

The diagnostic shift and difficulty in differentiating causes of death is compounded by mortality coding rules in the *International Statistical Classification of Diseases and Related Health Problems* (ICD).[20,21] ICD codes are applied to cause-of-death determinations used to certify sudden infant deaths, but the codes applied do not always reflect the certifier's intent.[15,16] By law, the official cause of death for these cases must be determined and reported by the medicolegal death investigation system (ie, medical examiner) and not by the pediatrician. Codes in the *International Statistical Classification of Diseases and Related Health Problems*, *10th Revision*, (ICD-10)[21] differ from those in the *International Statistical Classification of Diseases and Related Health Problems*, *10th Revision*, *Clinical Modification*, (ICD-10-CM).[37] The *ICD-10-CM* was adapted from the *ICD-10* for classifying and reporting diseases and other morbidities in US health care settings. The *ICD-10*, not the *ICD-10-CM*, is used for official reporting of mortality statistics in the United States and other nations.

For mortality surveillance that relies on ICD coding from death certificates, it has become customary in the United States to group sudden infant death causes into 1 of 3 categories: SIDS (ICD-10 code R95), unknown or unspecified causes (ICD-10 code R99), and accidental suffocation and strangulation in bed (ICD-10 code W75). These 3 causes are included in the larger category called SUID.[3,29,30] This larger category allows for consistent monitoring of mortality trends and comparisons across jurisdictions and includes deaths from both explained (ie, accidental suffocation and strangulation in bed) and unexplained causes (ie, SIDS, unknown and unspecified causes). For research purposes, this categorization may be reasonable if the goal is to capture all SUIDs initially and then, after a careful examination and assessment, further categorize deaths to meet a study's case definition of an unexplained or explained cause.

IMPORTANCE OF CONSISTENT TERMINOLOGY

When an infant dies, shared and consistent terminology is essential to help pediatricians, other physicians, and nonphysician clinicians (eg, family physicians, obstetricians, nurses, social workers, and home visitors) improve communication with families and among themselves. A lack of consistent practices and consensus on terminology, including the use of acronyms, creates confusion for and possibly alienation of stakeholders and partners: including parents, caregivers, pediatricians, program prevention planners, and other medical and scientific professionals. The current use of inconsistent terminology can lead to communication errors and unnecessary misunderstandings. It can affect the development of public policies designed to reduce sleep-related infant deaths, including child product safety legislation and regulation focused on promoting safe sleep environments. Inconsistent terminology may also have unintended consequences for prevention messages and interventions for parents and caregivers. In addition, it can negatively affect the bereavement response and support being provided after a sudden infant death.

HOW TO SENSITIVELY COMMUNICATE WITH PARENTS

After an infant death, pediatricians, other physicians, and nonphysician clinicians (especially hospital-based physicians) are often the ones who first speak to grieving parents about possible causes of death. Shared consistent terminology during these interactions with families is necessary for effective communication. Pediatricians, other physicians, and nonphysician clinicians serving the infant's family members continue their support of families through counseling and assessment of surviving siblings for potential shared congenital or genetic conditions. Increasingly, they participate in multidisciplinary child death reviews, consult with forensic medical specialists, and help support families through the investigation process, providing resources and referrals after the death. These physicians and nonphysician clinicians, especially pediatricians,

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are crucial and trusted sources of information for families and communities, facilitating the adoption of safe sleep practices and other strategies to reduce the risk of infant sleep-related deaths.[7]

It is important, when communicating with families after an infant death, to not assign blame to the family or incite feelings of guilt, while at the same time acknowledging potentially unsafe behaviors or hazards in the environment to effectively message how risks in the prenatal period or unsafe sleep practices may continue to pose a risk to surviving or subsequent children. The appropriate ethical medical professional response to every child death must be compassionate, empathic, supportive, and nonaccusatory, even if child abuse is suspected.

Concerns about unsafe sleep and bed-sharing as possible contributors to a child's death should be shared with parents as appropriate at some time during the investigation. Several resources have been developed to facilitate this sensitive communication. The AAP and others have identified key principles and resources to assist pediatricians, other physicians, and nonphysician clinicians and families during investigation. Recommendations for these discussions for families include saying things like "I am so sorry for your loss," "I am here to help," and "I have some resources that might be of help. They have been helpful to others." It is important for pediatricians, other physicians, and nonphysician clinicians to be truthful and sensitive, while sharing their willingness to help the family understand the death, the status of the investigation, and what steps, if any, should be taken to help surviving family members, including but not limited to evaluations for potential underlying conditions or referrals to pediatric specialists and mental health professionals.[38–45]

PROGRESS ON REACHING CONSENSUS

There are implications in reaching consensus on terminology to consider, including historical convention, uncertainty regarding circumstances at the time of death, geographical variations in practice, training of death-scene investigators and death certifiers, and caregiver guilt and shame. In addition, several perspectives must be addressed. First, it is essential for the forensic community and health care professionals to incorporate terminology that avoids placing blame or increasing feelings of guilt on the part of a caregiver suffering a tragic loss and objectively and accurately describes the circumstances around an infant's death. Second, the medical examiner or coroner needs to effectively communicate investigation and autopsy findings and explain why the conclusions about cause of death may be inconclusive. Third, the forensic, pediatric, and public health communities need consistent communication tools to allow them to acknowledge unsafe behaviors (eg, bed-sharing) or the presence of hazards in the environment (eg, crib bumpers or soft bedding) without assigning blame or inciting feelings of guilt. Finally, pediatricians, other physicians, and nonphysician clinicians must effectively message how risks identified in the prenatal period (eg, smoking and drinking during pregnancy) or unsafe sleep practices may continue to pose a risk to surviving children. The goal of this careful communication is to prevent from assigning blame or increasing feelings of guilt of any party. It is important that the facts and potential contributing factors to a death be fully shared. In sharing this information, it is important to provide accurate information regarding the deceased but also to identify and address any preventable risk factors for future children or circumstances.

Although there is agreement that all infant deaths are tragic events with precious lives lost, there is a need to consistently classify these sudden infant deaths for which the cause remains undetermined or unexplained. Consensus is also needed on how to classify accidental suffocation deaths that occur in an unsafe sleep environment: that is, what evidence is needed to classify a death as an explained suffocation in the absence of a biological marker to determine the cause. Current terminology and acronyms may exacerbate confusion. Consistency in describing these deaths should be a key goal. In 2017, a group of US experts came together to find common ground for classifying sudden infant deaths.[10] The group, the National Association of Medical Examiners (NAME) Panel on Sudden Unexpected Death in Pediatrics, included forensic pathologists representing NAME, pediatricians representing the AAP, and federal liaisons from the Centers for Disease Control and Prevention and NIH. In addition, in November 2018, an international expert panel (forensic pathologists, pediatricians, emergency physicians, family physicians, researchers, epidemiologists, and parents) met to discuss the terminology and nomenclature for sudden infant and child deaths at Radcliffe College, making ICD coding recommendations to the World Health Organization (WHO) for *International Statistical Classification of Diseases and Related Health Problems, 11th Revision* (*ICD-11*).[15] Many participants from the Radcliffe Congress meeting also participated in the NAME Panel. Both groups acknowledged that the forensic pathology experts had moved away

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from calling these deaths "SIDS" and had rejected the idea that the etiology of these deaths satisfied the definition of a syndrome. Regardless, researchers at the Radcliffe meeting, many with 30 to 40 years of SIDS experience, still preferred the term "SIDS." Forensic pathologists at the Radcliffe Congress agreed with other participants that the title of the code in ICD-11 should include both unexplained sudden death in infancy and SIDS, to reflect that both certifications could be classified under the same code (Table 1). This recommendation was echoed by the NAME Panel in its 2019 publication.[10] In addition, the NAME Panel recommended that certifiers use "unexplained sudden death" (and not SIDS) and specify whether intrinsic and extrinsic risk factors (Table 1) were identified in the cause-of-death statement for unexplained sudden pediatric (infants <1 year and children 1 year old and older) deaths, including those that meet the current definition of SIDS (Table 1). Both groups also identified a set of criteria for determining accidental suffocation as a cause in sleep-related deaths.

PRACTICAL CONSIDERATIONS

The lack of consistency in how sudden infant deaths are categorized or described across the United States has created confusion and has had unintended consequences for bereaved families, pediatricians, other physicians, nonphysician clinicians, and policymakers. In addition, inaccurate and inconsistent classification of sudden infant deaths has affected our ability to: (1) reliably and accurately monitor mortality trends; (2) understand the pathophysiology and epidemiology of sudden infant deaths; and (3) develop effective data-driven public health and preventive messages.[3,10,15] It remains to be seen whether the WHO will accept the changes proposed by the Radcliffe Congress for ICD classification and coding of unexplained sudden deaths; as of August 2021, this proposal is under review. The *ICD-11* will officially go into effect among WHO member states in January 2022. It is also too early to determine to what extent the forensic community will adopt the NAME Panel's recommendations and use of the phrase "unexplained sudden death."

Because pediatricians, other physicians, and nonphysician clinicians are often the conduit of information between bereaved families and medical examiners, coroners, and death-scene investigators, it is important for these health care professionals to be cognizant of the terminology used and its implications to enable them to help families, review deaths, and prevent further fatalities. In response, the AAP recommends the following:

- Advocating for the rapid adoption of the NAME Panel's terminology because the terminology is definitive and positioned to aid surveillance monitoring activities and epidemiological analysis.[10,14] Increased understanding of mortality trends, etiology, and risk factors can inform effective interventions and guide future research, ultimately reducing future fatalities.
- If the proposal of the Radcliffe Congress for changing the ICD classification and coding of unexplained sudden deaths is approved by the WHO, encouraging adaption of ICD-11 coding by the United States and other WHO member states by January 2022.
- Advocating that state child protective service agencies use the NAME Panel's terminology in their assessments.
- NAME, in collaboration with the AAP, should develop an algorithm to lead a medical examiner, through consideration of the history, the findings at the scene, and possible intrinsic and extrinsic contributing factors, to the final adjudication of cause of death.
- Encouraging the medical examiner to have a formal reporting mechanism back to the primary care pediatrician, other physician, or nonphysician clinician. The pediatrician, other physician, or nonphysician clinician should, in turn, offer the family a chance to meet and review the findings of any investigation, including discussing possible contributing or confounding factors that may have played a role in the infant's death and possibly be used to prevent future deaths and providing any needed referrals for pediatric specialist or mental health care.
- Training for physicians, nonphysician clinicians, and the forensic community about effective communication practices that prioritize empathy and sensitivity in sudden infant death and all fatality investigations.
- Affirmation that when child abuse is eliminated, other risk factors such as sleeping environment, drug or alcohol use of caregivers, prenatal exposures, and poverty are matters of public health and family health. The mere presence of risk factors should not support legal charges.

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ABBREVIATIONS

AAP: American Academy of Pediatrics
ICD: *International Statistical Classification of Diseases and Related Health Problems*
ICD-10: *International Statistical Classification of Diseases and Related Health Problems, 10th Revision*
ICD-10-CM: *International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Clinical Modification*
ICD-11: *International Statistical Classification of Diseases and Related Health Problems, 11th Revision*
NAME: National Association of Medical Examiners
NIH: National Institutes of Health
SIDS: sudden infant death syndrome
SUID: sudden unexpected infant death
WHO: World Health Organization

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