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NATIONAL ASSOCIATION OF MEDICAL EXAMINERS

CLINICAL REPORT
Guidance for the Clinician in Rendering Pediatric Care

Distinguishing Sudden Infant Death Syndrome From Child Abuse Fatalities

ABSTRACT. Fatal child abuse has been mistaken for sudden infant death syndrome (SIDS). When a healthy infant younger than 1 year dies suddenly and unexpectedly, the cause of death often is certified as SIDS. SIDS is more common than infanticide. Parents of SIDS victims typically are anxious to provide unlimited information to professionals involved in death investigation or research. They also want and deserve to be approached in a nonaccusatory manner. This clinical report provides professionals with information and guidelines to avoid distressing or stigmatizing families of SIDS victims while allowing accumulation of appropriate evidence in potential cases of infanticide. This clinical report addresses deficiencies and updates recommendations in the 2001 AAP policy statement of the same name.

Key words: sudden infant death syndrome, SIDS, child abuse.

INTRODUCTION

Approximately 50 years ago, the medical community began a search to understand and prevent sudden infant death syndrome (SIDS).[1,2] Almost simultaneously, medical professionals were awakened to the realities of child abuse.[3-6] Since then, public and professional awareness of SIDS and fatal child abuse during infancy have increased steadily. More recently, well-validated reports of child abuse and infanticide—intentional suffocation presenting as apparent life-threatening events (ALTEs) and/or apparent SIDS—have appeared in the medical literature and in the lay press.[7,8] The differentiation between SIDS and fatal child abuse can be a critical diagnostic decision.[9] Additional funding for research into the causes and prevention of SIDS and child abuse is needed.

For more than a decade, SIDS, also called crib or cot death, has been defined as the sudden death of an infant younger than 1 year that remains unexplained after thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history.[10] Very recently, an expert panel of pediatric and forensic pathologists and pediatricians proposed a new definition of SIDS that is stratified to facilitate research, administrative, and vital statistics purposes.[11] SIDS is the most common cause of death between 1 and 6 months of age. The incidence of SIDS peaks between 2 and 4 months of age. Approximately 90% of SIDS cases occur before the age of 6 months.[12]

SIDS is suspected when a previously healthy infant, usually younger than 6 months, apparently dies during sleep, prompting an urgent call for emergency assistance. Often, the baby is fed normally just before being placed in bed to sleep, no outcry is heard, and the baby is found in the position in which he or she had been placed at bedtime or naptime. In some cases, cardiorespiratory resuscitation initiated at the scene is continued without apparent beneficial

effect en route to the hospital, where the baby is finally declared dead. Evidence of terminal motor activity, such as clenched fists, may be seen. There may be serosanguineous, watery, frothy, or mucoid discharge coming from the nose or mouth. Skin mottling and postmortem lividity in dependent portions of the infant's body are commonly found. Review of the medical history, scene investigation, radiographs, and autopsy are unrevealing.

Despite extensive research, our understanding of the causes of SIDS remains incomplete.[13] The discovery of abnormalities in the arcuate nucleus of the brainstems of some SIDS victims suggests that true SIDS cases likely reflect delayed development of arousal, cardiorespiratory control, or cardiovascular control.[14,15] When the physiologic stability of such infants becomes compromised during sleep, they may not arouse sufficiently to avoid the noxious insult or condition.[16]

The SIDS rates are 2 to 3 times higher among black, Alaska Native, and some American Indian populations. SIDS has been linked epidemiologically in research studies to prone sleep position, sleeping on a soft surface, bed sharing, maternal smoking during or after pregnancy, overheating, late or no prenatal care, young maternal age, prematurity, low birth weight, and male gender.[13,17-25] To date, no definitive evidence establishes causality between SIDS and recurrent cyanosis, apnea, ALTEs, or immunizations during infancy.

In recent years, national campaigns aimed at reducing prone sleeping during infancy have succeeded in dramatically decreasing the prevalence of prone positioning and may be associated with a decrease in the incidence of SIDS in the United States and in other countries.[16,26-31] Many of these educational campaigns have also emphasized prompt evaluation and treatment of sick infants, appropriate immunizations, breastfeeding, and avoidance of bed sharing, overheating,

overdressing or overbundling, gestational or postnatal passive smoke exposure, and soft sleep materials or surfaces.

SIDS: A Diagnosis of Exclusion

The diagnosis of SIDS is exclusionary and requires a complete autopsy, investigation of the circumstances of death,[32] and review of case records that fail to reveal another cause of death. Infant deaths without such a comprehensive death investigation and cases that are autopsied and carefully investigated but reveal substantial and reasonable uncertainty regarding the cause or manner of death should be designated as undetermined. Examples of undetermined cases include suspected (but unproven) infant death attributable to infection, metabolic disease, asphyxiation, or child abuse.

A diagnosis of SIDS reflects the clear admission by medical professionals that an infant's death remains unexplained. A young infant's death should be ruled as attributable to SIDS when all of the following are true:

- A complete autopsy is performed, including examination of the cranium, the cranial contents, and the eyes and orbital tissues, and autopsy findings are compatible with SIDS;
- There is no evidence of acute or remote inflicted trauma, significant bone disease, or significant and contributory unintentional trauma, as judged by skeletal radiologic survey,[33] postmortem examination, and reliable clinical history;
- Other causes of death are sufficiently excluded, including meningitis, sepsis, aspiration, pneumonia, myocarditis, trauma, dehydration, fluid and electrolyte imbalance, significant congenital defects, inborn metabolic disorders, asphyxia, drowning, burns, or poisoning;
- There is no evidence of toxic exposure to alcohol, drugs, or other substances; and

- Thorough death and/or incident scene investigation and review of the clinical history reveal no other cause of death.

Child Abuse Fatalities by Suffocation

In some cases, it is difficult to differentiate between a natural unexplained infant death and an unnatural (intentional) infant death. Recent literature has suggested that the index of suspicion for unnatural death should be higher, particularly in families in which an unexplained infant death has occurred previously.[34] More recent publications, however, provide some reassurance that most recurrent, unexplained infant deaths are, in fact, natural.[35,36]

Estimates of the incidence of infanticide among cases designated as SIDS range from less than 1% to 5%.[7,9,37-39] The parents of some babies with recurrent ALTEs have been observed trying to suffocate and harm their babies.[7,40] In Great Britain, covert video surveillance was used to assess child abuse risk in 39 young children referred for evaluation of recurrent ALTEs.[7] Abuse was revealed in 33 of 39 cases, with documentation of intentional suffocation observed in 30 patients. Among 41 siblings of the 39 infants in the studies, 12 had previously died suddenly and unexpectedly. Although 11 of these deaths had been classified as SIDS, 4 parents later admitted to suffocating 8 of these siblings. Other cases previously thought to be multiple SIDS cases within a family[40,41] have been revealed to be cases of multiple homicide by suffocation.[8,34]

It is difficult, if not impossible, to distinguish at autopsy between SIDS and accidental or deliberate asphyxiation with a soft object.[42] However, certain circumstances could indicate the possibility of intentional suffocation, including:

- recurrent cyanosis, apnea, or ALTE occurring only while in the care of the same person;
- age at death older than 6 months; previous unexpected or unexplained deaths of one or more siblings;

- simultaneous or nearly simultaneous death of twins[43];
- previous death of infants under the care of the same unrelated person[44]; or
- evidence of previous pulmonary hemorrhage (such as marked siderophages in the lung).

Management of Sudden Unexpected Infant Death

Most sudden infant deaths occur at home. Parents are shocked, bewildered, and distressed. Parents who are innocent of blame in their child's death often feel responsible nonetheless and imagine ways in which they might have contributed to or prevented the tragedy.[45] The appropriate professional response to every child death must be compassionate, empathic, supportive, and nonaccusatory. Inadvertent comments, as well as necessary questioning by medical personnel and investigators, are likely to cause additional stress. It is important for those in contact with parents during this time to remain supportive and nonaccusatory, even while conducting a thorough death and/or incident scene investigation.

Personnel on first-response teams should be trained to make observations at the scene, including position of the infant, marks on the body, body temperature and rigor, type of bed or crib and any defects, amount and position of clothing and bedding, room temperature, type of ventilation and heating, and reaction of the caregivers. Guidelines are available for investigation of the circumstances of sudden, unexplained infant deaths.[32,37] Paramedics and emergency room personnel should be trained to distinguish normal findings, such as postmortem anal dilation and lividity, from trauma attributable to abuse.[46,47]

When a previously healthy infant has died unexpectedly in the absence of external evidence of injury or initial history/scene findings suggestive of another cause/manner of death, then a preliminary diagnosis of "possible SIDS" can be given. Assignment of this preliminary diagnosis should not limit or prevent subsequent thorough case investigation. Parents should be

informed that other causes of death will be excluded only by thorough investigation of the circumstances of death, postmortem examination, and review of case records. It should be explained to parents that these procedures might enable them and their physician to understand why their infant died and how other children in the family, including children born later, might be affected. Only on completion of a thorough case investigation (including performance of a complete autopsy, examination of the circumstances of death, and review of the clinical history) that does not reveal another cause of death should a diagnosis of SIDS be assigned as the cause of death.

If permitted by the medical examiner, the family should be given an opportunity to see and hold the infant once death has been pronounced. A protocol[48] may help in planning how and when to address the many issues that require attention, including baptism, grief counseling, funeral arrangements, religious support, termination of breastfeeding, and the reactions of surviving siblings.[45,49] All parents should be provided with information about sudden infant death[50,51] and the telephone number of the local SIDS support group.[48]

Controversy exists in the medical literature regarding the likelihood of a repetition of SIDS within a sibship.[52-55] When an infant's sudden and unexpected death has been thoroughly evaluated and alternate genetic, environmental, accidental, or inflicted causes of death have been carefully excluded, parents should be informed that the risk of SIDS in subsequent children is not likely increased. Although repetitive sudden and unexpected infant deaths occurring within the same family should compel investigators to consider the possibility of serial homicide,[8] it is important to remember that serial infant deaths within a sibship can also be explained by a fatal, inheritable disorder or by an unrecognized environmental hazard.

Distinguishing SIDS From Child Abuse Fatalities

In many states, multidisciplinary teams have been established to review child fatalities.[56,57] Ideally, a multidisciplinary death review committee should include a child welfare/child protective services social worker, a law enforcement officer, a public health officer, the medical examiner/coroner, a pediatrician with expertise in child maltreatment, a forensic pathologist, a representative of the emergency medical services (EMS) system, a pediatric pathologist, and the local prosecutor. The proceedings of multidisciplinary death review committees should remain confidential. Sharing data among agencies helps ensure that deaths attributable to child abuse are not missed and that surviving and subsequent siblings are protected. Some child fatality teams routinely review infant deaths attributable to apparent SIDS.

The Importance of Autopsy, Scene Investigation, and Case Review

The failure to differentiate fatal child abuse from SIDS is costly. In the absence of postmortem examination, investigation of the circumstances of death, and case review, child maltreatment is missed, familial genetic diseases go unrecognized, public health threats are overlooked, inadequate medical care goes undetected, product safety issues remain unidentified, and progress in understanding the etiology of SIDS and other causes of unexpected infant death is delayed. Inaccurate vital statistics lead to inappropriate allocation of limited health care resources. By thoroughly investigating apparent SIDS cases, the potential hazards of defective infant furniture, water beds, and bean bag mattresses have been identified and remedied.[58,59]

If appropriate toxicologic tests are not performed, infant deaths attributable to accidental or deliberate poisoning will be missed.[46,60] For example, occult cocaine exposure is potentially lethal. One review found that 17 (40%) of 43 infants who died before 2 days of age without an obvious cause of death at autopsy had toxicologic evidence of cocaine exposure.[61] A second review of 600 infant deaths revealed evidence of cocaine exposure in 16 infants (2.7%) younger

than 8 months who died suddenly and unexpectedly.[62] "Lethal" concentrations of cocaine and many other drugs in infancy are not yet established.

Neither child abuse nor SIDS is rare. Some young victims of nonlethal child maltreatment will die from SIDS. In such cases, the failure to differentiate objectively between fatal child abuse and SIDS could result in an inappropriate criminal investigation and/or prosecution for homicide.

Postmortem Imaging

Radiographic skeletal surveys performed before autopsy in cases of possible SIDS may reveal evidence of traumatic skeletal injury or skeletal abnormalities indicative of a naturally occurring illness. The skeletal survey should be performed in a manner comparable to that recommended for living infants in whom abuse is suspected[63,64] and reviewed by a physician experienced in identifying the subtle radiologic alterations seen with abuse, as well as findings that can be confused with inflicted injuries. Thorough documentation of all sites of suspected skeletal injury may require specimen resection, high-detail specimen radiography, and histologic analysis. The presence of both old and new traumatic injuries identified on skeletal survey before autopsy suggests inflicted injuries and may lend focus to the postmortem examination, investigation of the circumstances of death, and police investigation.[33,65]

Pathology

The American Academy of Pediatrics (AAP) and the National Association of Medical Examiners (NAME) endorses universal performance of autopsies on infants who die suddenly and unexpectedly by examiners experienced in the diagnosis of SIDS.[66] Postmortem findings in cases of fatal child abuse most often reveal cranial injuries, retinal hemorrhages, abdominal trauma (eg, liver laceration, hollow viscous perforation, or intramural hematoma), burns, or

drowning as the cause of death.[67-70] Intrathoracic petechiae are identified in 80% to 85% of SIDS cases but are not pathognomonic. Although cytomegalovirus inclusion bodies have been identified in some infants who died suddenly and unexpectedly, a definitive causal link between cytomegalovirus infection and SIDS has not been established.[71] Pathologists establish the diagnosis of SIDS by exclusion when they are unable to identify other specific causes for a child's death.[46]

Inborn errors of metabolism[72-74] have been implicated to cause a small percentage of sudden unexplained deaths in infants with autopsy findings consistent with SIDS. When repetitive, sudden, and unexpected infant deaths occur within a sibship, thorough evaluation to exclude or confirm an inborn error of metabolism is essential. Analysis of blood or other body fluids (urine, vitreous humor, cerebrospinal fluid, bile, and stomach contents collected and stored at –80°C) and brain, liver, kidney, heart, muscle, adrenal gland, and/or pancreas tissue may facilitate diagnosis of a fatal inborn error of metabolism. Blood tests for evaluation of many metabolic disorders are now available at low cost. Many medical examiners routinely screen all infants for inborn errors of metabolism at autopsy.

CONCLUSIONS

The following are important components in the evaluation of sudden, unexplained infant deaths:

- Accurate history taking by emergency responders and medical personnel at the time of death and made available to the medical examiner or coroner;
- Prompt investigation of the scene[32,37] where the infant was found lifeless or unresponsive and careful interviews of household members by knowledgeable individuals (potentially including pediatrician);

- Appropriate use of available medical specialists (eg, pediatrician, pediatric pathologist, pediatric radiologist, and/or pediatric neuropathologist) by medical examiners and coroners;
- Complete autopsy performed by a forensic pathologist within 24 hours of death, including examination of the cranium, the cranial contents, and the eyes and orbital tissues; radiographic skeletal survey; and toxicologic and metabolic screening;
- Collection of medical history through interviews of caregivers, interviews of key medical providers, and review of previous medical records;
- Maintenance of a supportive approach to parents during the death review process;
- Consideration of intentional asphyxiation in cases of unexpected infant death with a history of recurrent cyanosis, apnea, or ALTEs witnessed only by a single caregiver;
- Use of accepted diagnostic categories on death certificates as soon as possible after review;
- Prompt informing sessions with parents when results indicate SIDS, accidental, or medical causation of death; and
- Review of collected data by locally based infant death review teams[57] with participation of the medical examiner or coroner.

The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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