AMERICAN ACADEMY OF PEDIATRICS

Committee on Child Abuse and Neglect

Distinguishing Sudden Infant Death Syndrome From Child Abuse Fatalities

ABSTRACT. In most cases, when a healthy infant younger than 1 year dies suddenly and unexpectedly, the cause is sudden infant death syndrome (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 statement 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 death by infanticide.

ABBREVIATIONS. SIDS, sudden infant death syndrome; ALTE, apparent life-threatening events.

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. Recently, well-validated reports of child abuse and infanticide—perpetrated by suffocation and masqueraded as apparent life-threatening events (ALTE) and/or 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.

SIDS: EPIDEMIOLOGY, PRESENTATION, AND RISK FACTORS

SIDS, also called crib or cot death, is the sudden death of an infant under 1 year of age that remains unexplained after thorough case investigation, including performance of a complete autopsy, examination of the death scene, and a review of the clinical history.[10] 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 deaths occur before the age of 6 months.[11]

SIDS is suspected when a previously healthy infant, usually younger than 6 months, is found dead in bed, 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 by emergency personnel 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, understanding of the etiology of SIDS remains incomplete. The discovery of abnormalities in the arcuate nucleus of the brainstems of some SIDS victims suggests that true SIDS deaths likely reflect delayed development of arousal, cardiorespiratory control, or cardiovascular control.[12,13] When the physiologic stability of such infants becomes compromised during sleep, they may not arouse sufficiently to avoid the noxious insult or condition.[14]

The SIDS rates are 2 to 3 times higher among African American and some American Indian populations. SIDS has been linked etiologically in research studies to prone sleep position, sleeping on a soft surface, maternal smoking during or after pregnancy, overheating, late or no prenatal care, young maternal age, prematurity, low birth weight, and male gender.[15–23] To date, no definitive evidence establishes causality between SIDS and recurrent cyanosis, apnea, ALTE, or immunizations during infancy. When recurrent cyanosis, apnea, or ALTE during infancy are reported, pediatricians should document these events objectively and determine if or not these events have occurred in the presence of more than 1 caregiver.

In recent years, national campaigns aimed at reducing prone sleeping during infancy have dramatically decreased the incidence of SIDS in the United States and in other countries.[14,24–29] Many of these educational campaigns have also emphasized prompt evaluation and treatment for sick infants, appropriate immunizations, breastfeeding, and avoidance of overlying, overheating, overwrapping, gestational or postnatal passive smoke exposure, and soft sleep materials or surfaces.

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

SIDS: A DIAGNOSIS OF EXCLUSION

The diagnosis of SIDS is exclusionary and requires a postmortem examination, death scene investigation,[30] and review of case records that fail to reveal another cause of death. Infant deaths without postmortem examination should not be attributed to SIDS. Cases that are autopsied and carefully investigated but reveal substantial and reasonable uncertainty regarding the cause or manner of death may be designated as undetermined. Examples of undetermined cases include suspected (but unproven) infant death attributable to infection, metabolic disease, accidental asphyxiation, or child abuse.

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

- a complete autopsy is done, including cranium and cranial contents, and autopsy findings are compatible with SIDS;
- there is no gross or microscopic evidence of trauma or significant disease process;
- there is no evidence of trauma on skeletal survey[31];
- other causes of death are adequately ruled out, including meningitis, sepsis, aspiration, pneumonia, myocarditis, abdominal trauma, dehydration, fluid and electrolyte imbalance, significant congenital lesions, inborn metabolic disorders, carbon monoxide asphyxia, drowning, or burns;
- there is no evidence of current alcohol, drug, or toxic exposure; and
- thorough death scene investigation and review of the clinical history are negative.

CHILD ABUSE FATALITIES BY SUFFOCATION

As the occurrence of cases of true SIDS has decreased, the proportion of unexplained infant deaths attributable to fatal child abuse may be increasing.[32] Estimates of the incidence of infanticide among cases designated as SIDS range from <1% to 5%.[7,9,33–35]

Parents of infants with recurrent ALTEs have been observed trying to suffocate and harm their infants.[7,36] 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 deaths within a family[37] have been revealed to be cases of multiple homicide by suffocation.[8,32]

It is impossible to distinguish at autopsy between SIDS and accidental or deliberate asphyxiation with a soft object.[38] However, certain circumstances should indicate the possibility of intentional suffocation, including:

- previous recurrent cyanosis, apnea, or ALTE while in the care of the same person;
- age at death older than 6 months;
- previous unexpected or unexplained deaths of 1 or more siblings;
- simultaneous or nearly simultaneous death of twins[39];
- previous death of infants under the care of the same unrelated person[40]; or
- discovery of blood on the infant's nose or mouth in association with ALTEs.[7]

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.[41,42] The appropriate professional response to any 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 be supportive while at the same time conducting a thorough 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 death scene investigation of sudden, unexplained infant deaths.[30,33] Paramedics and emergency department personnel should be trained to distinguish normal findings, such as postmortem anal dilation and lividity, from trauma attributable to abuse.[42,43]

When a previously healthy infant has died unexpectedly in the absence of external evidence of injury, a preliminary diagnosis of "probable SIDS" can be given. To the family of a true victim of SIDS, this diagnosis conveys the health care provider's initial impression that they could not have prevented their infant's death. 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 death scene investigation, 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 and negative case investigation (including performance of a complete autopsy, examination of the death scene, and review of the clinical history) should a definitive diagnosis of SIDS be assigned as the cause of death.

The family is entitled to an opportunity to see and

hold the infant once death has been pronounced. A protocol[44] may help in planning how and when to address the many issues that require attention, including baptism, grief counseling, funeral arrangements and religious support, cessation of breastfeeding, and the reactions of surviving siblings.[41,45] All parents should be provided with information about SIDS[46,47] and the telephone number of the local SIDS support group.[46]

Controversy exists in the medical literature regarding the likelihood of a repetition of SIDS within a sibship.[48–51] When an infant's sudden and unexpected death has been thoroughly evaluated and alternate environmental or accidental causes of death have been carefully excluded, parents should be informed that the risk for SIDS in subsequent children is not likely increased.

In many states, multidisciplinary teams have been established to review child fatalities.[52,53] 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 pediatric pathologist, and the local prosecutor.[53] 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, death scene investigation, 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 deaths, the potential hazards of defective infant furniture, water beds, and beanbag mattresses have been identified and remedied.[54,55]

If appropriate toxicologic tests are not done, the few infant deaths attributable to accidental or deliberate poisoning will be missed.[42,56] Occult cocaine exposure is widespread and 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.[57] 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.[58] Lethal concentrations of cocaine and many other drugs in infancy are not yet established.

POSTMORTEM IMAGING

Radiographic skeletal surveys performed before autopsy in cases of suspected SIDS may reveal evidence of traumatic skeletal injury or skeletal abnormalities indicative of a naturally occurring illness. Thorough documentation of all sites of suspected skeletal injury may require specimen resection and high-detail specimen radiography. The presence of old and new inflicted traumatic injuries identified on skeletal survey before autopsy may lend focus to the postmortem examination, death scene investigation, and police investigation.[31,59]

PATHOLOGY

The American Academy of Pediatrics endorses universal performance of autopsies on infants who die suddenly and unexpectedly.[60] An international standardized autopsy protocol is available for this purpose.[61] Postmortem findings in cases of fatal child abuse most often reveal cranial injuries, abdominal trauma (eg, liver laceration, hollow viscous perforation, or intramural hematoma), burns, drowning, or exposure as the cause of death.[62–65] Pathologists establish the diagnosis of SIDS by exclusion when they are unable to identify other specific causes for a child's death.[42]

Intrathoracic petechiae are identified in 80% to 85% of SIDS cases but are not pathognomonic. Substantial evidence regarding intrathoracic petechiae in human and experimental studies supports the hypothesis that upper airway obstruction is the final event in SIDS.[66]

Inborn errors of metabolism[67–69] have been implicated to cause a small percentage of sudden unexplained deaths in infants with autopsy findings consistent with SIDS. Although cytomegaloviral inclusion bodies have been identified in some infants who died suddenly and unexpectedly, a definitive causal link between cytomegaloviral infection and SIDS has not been established.[70] 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.

RECOMMENDATIONS

The Academy makes the following recommendations for 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 death scene investigation[30,33] where the infant was found lifeless and careful interviews of household members by knowledgeable individuals (potentially including a pediatrician);
- examination of the dead infant at a hospital emergency department by a child maltreatment specialist;

- postmortem examination following established protocol[57] within 24 hours of death, including radiographic skeletal survey, toxicologic, and metabolic screening;
- collection of medical history through interviews of caretakers, 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 ALTE witnessed only by a single caretaker or in a family with previous unexplained infant death(s);
- use of accepted diagnostic categories on death certificates as soon as possible after review;
- prompt informing sessions with parents when results indicate SIDS or medical causation of death; and
- locally based infant death review teams[49] to review collected data with participation of the medical examiner or coroner in the review.

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