CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

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Identifying Child Abuse Fatalities During Infancy

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When a healthy infant dies suddenly and unexpectedly, it is critical to correctly determine if the death was caused by child abuse or neglect. Sudden unexpected infant deaths should be comprehensively investigated, ancillary tests and forensic procedures should be used to more-accurately identify the cause of death, and parents deserve to be approached in a nonaccusatory manner during the investigation. Missing a child abuse death can place other children at risk, and inappropriately approaching a sleep-related death as maltreatment can result in inappropriate criminal and protective services investigations. Communities can learn from these deaths by using multidisciplinary child death reviews. Pediatricians can support families during investigation, advocate for and support state policies that require autopsies and scene investigation, and advocate for establishing comprehensive and fully funded child death investigation and reviews at the local and state levels. Additional funding is also needed for research to advance our ability to prevent these deaths.

INTRODUCTION

More than 60 years ago, the medical community began a search to understand and prevent the sudden unexpected deaths of apparently healthy infants. Sudden refers to the fact that death comes without warning, and unexpected means that there is no preexisting condition known that could have reasonably predicted it. In an effort to further study and categorize these deaths, the term sudden infant death syndrome (SIDS) was coined.[1,2] Almost simultaneously, medical professionals recognized the realities of child abuse.[3–6] Since then, public and professional awareness of sudden unexpected infant death and fatal child abuse have increased, and well-validated reports of homicide and child abuse have appeared in the medical literature and in the lay press.[7–9] The US Commission on the Elimination of Child Abuse and Neglect Fatalities has noted significant undercounting of child abuse fatalities and has called

abstract

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for improved identification and prevention of these deaths.[10] Differentiating deaths from abuse from sudden infant deaths that are unintentional, however, can be a difficult diagnostic decision.[11–13] Clinicians and pathologists need an appropriately high index of suspicion of abuse, and additional funding for improved identification and research into the causes and prevention of these fatalities is needed. This report updates a previous statement[14] on the basis of new publications from the American Academy of Pediatrics (AAP) and other updated research to assist in the identification and prevention of child maltreatment fatality.

SUDDEN UNEXPLAINED INFANT DEATH

The term SIDS was introduced in the 1960s as the medical community attempted to better identify and define the sudden, unexpected, and unexplained deaths of infants and young children.[15,16] Throughout the ensuing decades, there was an increase in the depth and breadth of autopsy procedures and ancillary testing and sophistication and detail of death investigation, including scene investigation and caregiver interviews. Knowledge has increased about less-obvious causes of death, such as inborn errors of metabolism, primary cardiac dysrhythmias, and occult seizures.[17,18] Coinciding with improved investigative techniques, there has been a diagnostic shift away from using SIDS as a cause of death, and in its place, many medical examiners and coroners classify infant deaths occurring in an unsafe sleep environment as having an "undetermined cause" or "accidental asphyxiation in an unsafe sleep environment" because they cannot attribute these deaths with certainty specifically to the sleep environment. Because of this diagnostic shift, sleep-related infant deaths are now often grouped as "sudden unexpected infant deaths."[19–21]

In the United States over a number of years through 2015, sudden unexpected infant death is the primary category of death in vital statistics for children between 1 and 12 months of age, with a peak incidence between 1 and 4 months of age, and with 90% of these before the age of 6 months.[21–23] Rates in 2013 were 2 to 3 times higher among non-Hispanic African American and American Indian or Alaskan Native children when compared with non-Hispanic white children (172.4 and 177.6 vs 84.5 deaths per 100 000 live births, respectively).[22] Increased risk for SIDS has been found in epidemiological studies with prone and side sleep positions, prenatal and postnatal tobacco and opioid exposure, sleeping on a soft surface, sharing a sleep surface with others, overheating, late or no prenatal care, young maternal age, preterm birth, low birth weight, and male sex.[24–30] Breastfeeding, pacifier use, immunizations, and room sharing without bed-sharing have been identified as protective factors. There is no evidence that recurrent episodes of cyanosis, apnea, or apparent life-threatening events (sometimes called "near-miss SIDS" and now called brief resolved unexplained events [BRUEs][11]) increase the risk.

Despite extensive research, our understanding of the causes of sudden unexpected infant death remains incomplete.[15] There have been varying guidelines published to facilitate research and administrative purposes with a growing consensus that these deaths can be described as unexplained only when:

1. A complete autopsy has been performed, including examination of the cranium and the cranial contents, and the gross and microscopic findings fail to demonstrate an anatomic cause of death;
2. There is no evidence of acute or remote inflicted trauma, significant natural disease, or significant and contributory unintentional trauma as judged by radiologic imaging, postmortem examination, and reliable clinical history;
3. Other causes and/or mechanisms of death, including meningitis, sepsis, aspiration, pneumonia, myocarditis, trauma, dehydration, fluid and electrolyte imbalance, significant congenital defects, inborn metabolic disorders, asphyxia, drowning, burns, and poisoning, have been sufficiently excluded as a cause of death;
4. Comprehensive testing has revealed no evidence of toxic exposure to alcohol, drugs, or other substances that may have contributed to death; and
5. Thorough review of the clinical history and death- and incident-scene investigation have revealed no cause of death.

CHILD MALTREATMENT FATALITY

Child abuse causes and contributes to infant death in a number of ways. In data from the US National Child Abuse and Neglect Data System, it was noted in 2016 that of the estimated 1750 child maltreatment deaths, almost half involved infants younger than 1 year, a rate of 20.63 per 100 000 children in the population younger than 1 year.[31] Most maltreatment fatalities are attributed to neglect, with or without additional physical abuse. Factors identified in families with increased risk for child maltreatment fatality include poverty, previous or current involvement with child protective services, unrelated male caregivers, and previous unexplained death or nonaccidental trauma of other infants.[32–37] In recent literature, it is suggested that natural or accidental deaths are more commonly reported than child abuse fatalities, with approximately 3700 sudden unexpected infant deaths in 2015 in the United States.[16] However, deaths reported as child maltreatment fatalities are believed to be underestimates, with more than triple

the number officially reported being estimated to occur.[10,31]

Closed head injury is considered the leading cause of fatal abuse, with a peak incidence at 1 to 2 months of age, a time period that overlaps with sudden unexpected infant deaths.[38] Several findings, such as subdural hematoma, retinal hemorrhages, optic nerve sheath hemorrhages, rib fractures, and classic metaphyseal lesions, have most frequently been identified.[39] Characteristics may include the absence of a history of trauma as well as the absence of external evidence of impact to the head, skull fractures, subdural hemorrhage, or hypoxic-ischemic changes. Some additional causes of child abuse fatalities have been found to be intentional asphyxia; abdominal, thoracic, and other trauma; and poisoning.[30]

It may be difficult to differentiate among a natural infant death, an unintentional or accidental infant death, and an intentional or neglectful infant death when findings of maltreatment are absent. Parents have been observed trying to suffocate and harm their infants,[7,40–42] and estimates of the incidence of infanticide among cases designated as sudden infant death have ranged from 1% to 10%.[43] Certain circumstances in the medical history can indicate increased risk for intentional suffocation,[44] including:

- recurrent cyanosis, apnea, or BRUEs occurring only 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; and
- previous death of an infant under the care of the same unrelated person.

INITIAL MANAGEMENT OF SUDDEN UNEXPECTED INFANT DEATH

It is critical to identify whether child abuse or neglect has contributed to an infant's death. Missing a child abuse death can place other children at risk, and inappropriately labeling a sleep-related death as a homicide can result in an inappropriate criminal investigation and possible prosecution. Comprehensive medical evaluation, scene investigation, and autopsy are critical to improving identification and reporting of the cause of an infant's death.[45]

Most sudden unexpected infant deaths occur at home. Parents are shocked, bewildered, and distressed. Parents who are innocent of blame in their infant's death often feel responsible, nonetheless, and imagine ways in which they might have contributed to or prevented the tragedy, and they often feel remorse, guilt, and fear of consequences.[45] Grief and long-term effects of such stress are significant, especially for remaining children in the home.[46–50] The appropriate ethical medical professional response to every child death must be compassionate, empathic, supportive, and nonaccusatory.[51] Inadvertent comments and accusatory 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 nonaccusatory and to allow them to begin the process of grieving while a thorough death investigation is conducted. 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. The National Institute of Justice and National Institute of Standards and Technology have identified key principles and resources to assist medical examiners and families during investigation.[51]

The likelihood of a repetition of sudden unexpected infant death within a sibship in the medical literature is unclear.[52–54] Although repetitive sudden 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 infant deaths within a sibship can also be explained by a heritable disorder that is undefined and/or unrecognized at the time of investigation, 2 separate and unrelated natural disease processes, or an unrecognized environmental hazard. When an infant's sudden unexpected death has been thoroughly evaluated and alternate genetic, environmental, accidental, or inflicted causes have been carefully excluded, parents can be informed that the risk in subsequent children is not likely increased. Parents can be given a clearly stated, honest, and forthright conclusion, even if that conclusion lacks the solidity of a specific diagnosis, such as pneumonia or congenital heart disease.[55] Good communication with parents should include an adequate explanation that "undetermined" simply means "unable to be determined" or "we do not know." The term undetermined does not necessarily imply that a death is suspicious and should not diminish parental access to appropriate grief counseling. It can be explained to parents that the investigation 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.

Depending on local protocols and statutes, and if permitted by the medical examiner, the family may be given a supervised opportunity to see and hold the infant and collect materials once death has been pronounced.[56] It is suggested that an unrelated professional remain with the family throughout this period to serve as a witness should issues regarding postmortem artifacts arise. Professionals need to have the many immediate issues that require attention addressed, including baptism, grief counseling, funeral arrangements, religious support, resolution of breastfeeding, and the reactions of surviving siblings. All parents can be provided with information about sudden unexpected infant death and how to contact the

medical examiner's or coroner's office and local support groups.[57–59]

INVESTIGATION

It continues to be difficult to distinguish fatal child abuse by autopsy alone.[60,61] In the absence of a complete investigation of the circumstances of death and case review, child maltreatment is missed, familial and genetic diseases go unrecognized, public health threats are overlooked, inadequate medical care goes undetected, product safety issues remain unidentified, and progress in understanding the causes and mechanisms of unexpected infant death is delayed.[10,18,51,52,61,62] A thorough investigation can remove the shroud of suspicion while maintaining good communication with families.

A comprehensive scene investigation is one essential leg of a complete and thorough infant death investigation.[61] Personnel on first-response teams should have specific training to make observations at the scene, including position of the infant; marks on the body; pattern and distribution of livor mortis; rigor mortis; location of the infant when found, including type of bed, crib, or other sleep environment and any defects in it; amount and position of clothing and bedding; room temperature; type of ventilation and heating; and reaction of the caregivers. Medics and emergency department personnel should be trained to distinguish normal findings from trauma attributable to abuse. Death investigators should be trained and skilled in the recognition of potentially important environmental features, such as cigarette or other smoke, the presence of drugs or alcohol, sources of carbon monoxide in the sleep room of the deceased infant, or a wet bathtub or infant bathing area. Appropriate consultations by medical examiners and coroners with available medical specialists (eg, general pediatrician, child abuse pediatrician, pediatric pathologist, pediatric radiologist, and/or pediatric neuropathologist) can also be invaluable. Doll reenactment has become an increasingly valuable investigative tool, as well.[61]

If standard and case-appropriate toxicology tests are not performed, infant deaths attributable to accidental or deliberate poisoning will be missed.[63] In 1 review of autopsies in the early 1990s, it was found that 17 (40%) of 43 infants who died before 2 days of age without an obvious cause of death at autopsy had toxicological evidence of cocaine exposure.[64] In a separate review of 600 infant deaths, evidence of cocaine exposure in 16 infants (2.7%) younger than 8 months who died suddenly and unexpectedly was revealed.[65] Lethal concentrations of opioids, cocaine, and many other drugs are not well established in infancy, and blood and liver concentrations must always be interpreted in the context of the complete investigation.

POSTMORTEM IMAGING

Radiographic skeletal surveys and computed tomography (CT) imaging performed before autopsy may reveal evidence of traumatic skeletal injury or skeletal abnormalities indicative of a naturally occurring illness. The presence of both old and new traumatic injuries as well as fractures specific for abuse may suggest inflicted injuries and may lend focus to the postmortem examination, investigation of the circumstances of death, and police investigation. Ideally, such imaging should only be performed at the direction of the medical examiner or coroner, and it is helpful for medical examiners and coroners to create protocols for this to occur. The skeletal survey and/or CT scans should be performed according to American College of Radiology guidelines as recommended for living infants in whom abuse is suspected and reviewed by a radiologist experienced in identifying the sometimes subtle radiologic changes seen with abuse as well as findings that may be confused with inflicted injuries.[66] It is also important to review medical history for any previous medical encounters that included imaging that could show evidence of previous injuries or normal variants. Thorough documentation of all sites of suspected skeletal injury may require additional procedures, including, but not limited to, specimen resection, high-detail specimen radiography, CT, and histologic analysis to assess aging.

PATHOLOGY

For infants who die suddenly and unexpectedly, the AAP and the National Association of Medical Examiners have endorsed universal performance of autopsies by forensic pathologists experienced in the evaluation of infant death and qualified in forensic pathology by the American Board of Pathology. The forensic pathologist performing the autopsy should have access to specialists and reference laboratories for consultation and ancillary testing. Medical specialist consultants may include but are not limited to neuropathologists, ophthalmologic pathologists, pediatric neurologists, cardiac specialists, geneticists, pediatric pathologists, pediatric radiologists, and child abuse pediatricians. Reference laboratories may include but are not limited to postmortem toxicology laboratories, clinical pathology laboratories, and laboratories screening for inborn errors of metabolism. Historically, postmortem findings in cases of fatal child abuse have included evidence of intracranial injuries, retinal hemorrhages, abdominal trauma (eg, liver laceration, hollow viscous perforation, or intramural hematoma), fractures, bruises, burns, or drowning.[67–69]

Testing for inborn errors of metabolism is considered by many to be a routine ancillary test in the evaluation of an unexplained infant death. When these deaths have occurred more than once within a sibship, a thorough evaluation to exclude or confirm an inborn error of metabolism is essential.[70] Analysis of

blood and bile may facilitate diagnosis of a fatal inborn error of metabolism. Blood tests for evaluation of many metabolic disorders are now available at low cost, and many states include testing for a number of metabolic diseases on their newborn metabolic screening panel. However, a negative newborn screen result does not eliminate an inborn error of metabolism as the cause of death, so additional postmortem testing may be considered. If an inborn error of metabolism is suspected by autopsy findings (eg, hepatic steatosis) or history (eg, previous unexpected deaths in childhood in the family), the forensic pathologist may elect to retain additional tissues such as brain, liver, kidney, heart, muscle, adrenal gland, and/or pancreas for further analysis. In any case in which the medical examiner is unable to demonstrate an adequate reason for death, a blood sample can be retained for potential future analysis.

More recently, it has been suggested that genetic mutations associated with cardiac rhythm disturbances, such as prolonged QT syndrome, catecholaminergic ventricular paroxysmal tachycardia, and others, are responsible for up to 10% of cases of sudden unexpected infant death.[71,72] In addition, associations with sleep suggest that sleep is a significant risk factor for sudden unexpected death in epilepsy and that the prone position might be an important contributory factor.[73,74] Identification of a possible index case thus warrants referral of the family for comprehensive genetic counseling and additional testing. However, the cost of routine genetic testing may be beyond the capacity of some medical examiner's or coroner's offices, but it may be possible to obtain payment for genetic testing via the family's health insurance carrier.

MULTIDISCIPLINARY CASE REVIEW

Multidisciplinary case reviews of child fatalities have been recommended.[75] In all states, child death review teams have been established to review child fatalities, and improved case identification and evidence for prevention strategies in many jurisdictions are offered in such reviews.[76–78] The focus of such teams varies, ranging from infant or child deaths with accidental or homicidal manner to all childhood deaths from all causes. Many child fatality review teams routinely review sudden unexpected infant deaths. Ideally, a multidisciplinary child death review team should include child welfare or child protective services, law enforcement, public health, the medical examiner or coroner, a pediatrician with expertise in child maltreatment, a forensic pathologist, a representative of the emergency medical services system, a pediatric pathologist, public health and school officials, a local prosecutor, and other agencies pertinent to the case.[79] The proceedings of these committees should be confidential and protected by appropriate state or local laws. Sharing data among agencies should be allowed to ensure that information in community systems can be used to identify areas of prevention and to correctly attribute the cause of death. In addition, surviving and subsequent siblings may need to be protected, and services need to be provided for family members to address the immediate and long-term effects of the death. A growing number of pediatricians and medical examiners and coroners in several jurisdictions are currently receiving support from the Centers for Disease Control and Prevention for a sudden unexpected infant death case reporting system to review cases using standard data collection forms and procedures.[80,81]

RECOMMENDATIONS

The following recommendations are made to improve the identification of child abuse fatalities during infancy:

- A thorough assessment of each unexpected infant fatality should be completed. Such evaluation could include, but would not be limited to, careful history-taking by emergency responders and medical personnel at the time of death with transmission of this information to the medical examiner or coroner; prompt investigation with doll reenactment of the scene at which the infant was found lifeless or unresponsive; careful interviews of household members by knowledgeable, culturally sensitive professionals, such as police, death investigators, prosecutors, and child protective services professionals who have the legal authority and mandate to conduct such investigations; complete autopsy performed by a forensic pathologist within 24 hours of death, including examination of all major body cavities, including cranial contents and microscopic examination of major organs; photographs; radiographic examination, including skeletal survey; toxicological and metabolic screening; collection of medical history through interviews of caregivers and key medical providers; and review of previous medical charts.
- There should be consultations as needed with available local or in-state medical specialists (eg, pediatrician, child abuse pediatrician, pediatric pathologist, pediatric radiologist, pediatric neurologist) by medical examiners and coroners and consideration of intentional asphyxia, especially in cases of unexpected infant death in siblings and with a history of recurrent cyanosis, apnea, or BRUEs witnessed only by a single caregiver.
- Pediatricians, other health care professionals, and investigators should maintain an unbiased, nonaccusatory approach to parents during investigation and provide services or referral to address grief and stresses for surviving family members.
- Because an investigation may require an extended period of time,

pediatricians can advocate for proper death certification and prompt communication to parents and the use of consistent diagnostic categories on death certificates as soon as possible after review; work with families to obtain information from the medical examiner and offer to meet with families to review findings; reinforce Safe to Sleep guidelines for other children; and refer families to social services agencies as needed and for further assessment if potential inheritable conditions are identified.

- There should be review of collected data and prevention strategies by child death review teams with participation of the medical examiner or coroner. Child death review teams at both the state and local levels should include pediatricians who serve as expert members in reviewing case files of the medical examiner and other agencies, particularly for deaths of children who were their patients; information should be shared with providers caring for the family to the extent allowable by law.
- Pediatricians should continue to support the Safe to Sleep campaign and the adoption of safe sleep practices, child death review, and other strategies focusing on ways to reduce the risk of infant sleep-related and maltreatment deaths.
- Pediatricians can work with their state AAP chapters to advocate for and support state policies that require autopsies for sudden unexpected infant deaths and that establish comprehensive and fully funded child death investigation and review systems at the local and state levels. Pediatricians can also advocate for additional funding for research into the causes, identification, and prevention of sudden unexpected infant fatality.

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ABBREVIATIONS

AAP: American Academy of Pediatrics
BRUE: brief resolved unexplained event
CT: computed tomography
SIDS: sudden infant death syndrome

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