A Functional Approach to Sudden Unexplained Infant Deaths

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Abstract

There is a great deal of variation in the methods and wording used by medical examiners in the medicolegal investigation and certification of infant deaths. This paper was created by the NAME Ad Hoc Committee on Sudden Unexplained Infant Death to address several specific issues, namely:

- To establish a functional approach to the investigation of sudden unexplained infant deaths
- To outline a “bare minimum” set of recommendations to define the scope of investigation required
- To recommend methods and wording to be used when certifying infant deaths
- To develop a list of potential stressors or possible external causes of death that should be identified and reported on the death certificate and/or within a medical examiner/coroner office database

This paper was electronically posted for NAME member review and comment for a period of 30 days. The paper was further revised based on member comments, and then submitted to the NAME Board of Directors in the fall of 2005, prior to the Annual meeting. This text of this paper was officially approved and endorsed by the NAME Board of Directors on October 14, 2005, at the Annual Meeting in Los Angeles California.

Key Words: Sudden unexplained infant death, death certificate, infant death investigation

Introduction

This W*hite Paper* is intended to provide a functional approach to the investigation of sudden unexplained infant deaths. Sections include:

- Methods, with Basis for Recommendations
- Definitions
- Expected Scope of Investigation
- Critical General Questions
- Critical Specific Questions
- Cause-of-Death Reporting
- Reporting of possible Stressors, external causes, or gray zone findings
- Data and Other Issues

Methods

Basis for Recommendations

The recommendations in this *white paper* are based on multiple sources which include:

- The 1969 definition of Sudden Infant Death Syndrome (SIDS) [1]
- The 1989 definition of SIDS [2]
- Proposed redefinition of SIDS from 1993 [3]
- The Examination of the Sudden Infant Death Syndrome: Investigative and Autopsy Protocols (1976) [4]
- Histopathology Atlas of the Sudden Infant Death Syndrome (1993) [5]
- Guidelines for Death Scene Investigation of Sudden, Unexplained Infant Deaths: Recommendations of the Interagency Panel on Sudden Infant Death Syndrome (1996) [6]
- International Standardized Autopsy Protocol for Sudden Unexpected Infant Death (1996) [7]
- Death Investigation: A Guide for Death Scene Investigators (1997) [8]
- Distinguishing Sudden Infant Death Syndrome for Child Abuse Fatalities (2001) [9]
- CAP Guidelines regarding Autopsy Performance, Autopsy Reporting, Examination of Brain and Cord, Forensic Pathology, and Perinatal and Pediatric Pathology [10-14]
- Proposed NAME Standards for Forensic Pathology Practice [15]
- Draft revision of the Sudden Unexplained Infant Death Investigative Report Form (SUIDIRF) (2005) [16]
- Discussions held on NAME-L Listserv (2004)
- Medical Examiners' and Coroners' Handbook on Death Registration and Fetal Death Reporting (2003) [17]
- Re-evaluation and the 2004 suggested revision of the SIDS Definition [18-19]

- What is Essential in SIDOID Investigation? Manner of Death, and What's in a NAME? (2005) [20]
- Data regarding co-sleeping and similar stressors (2005) [21]

The above materials were reviewed with the goal of identifying:

- A functional approach to the investigation of sudden unexplained infant deaths
- A "bare minimum" set of recommendations to define the scope of investigation required
- Recommendations for methods to be used when certifying infant deaths
- A list of potential stressors or possible external causes of death that should be identified and reported on the death certificate and/or within a medical examiner/coroner office database

Preliminary proposals were developed and presented by one of the authors (RH) at the Interim Meeting of the National Association of Medical Examiners, New Orleans, February 22, 2005. Feedback was incorporated and a draft report was prepared for review by the NAME Board of Directors. After additional modifications, the draft was posted on NAME's website for a 30-day period of review and comment. The Committee then considered comments and prepared a final draft *white paper* for review and approval by the NAME Board of Directors. This version was approved by the NAME Board of Directors on October 14, 2005, at the Annual meeting in Los Angeles, California.

Results and Discussion

Definitions

Sudden unexplained infant death (SUID) applies to the death of an infant less than one year of age, in which investigation, autopsy, medical history review, and appropriate laboratory testing fails to identify a specific cause of death. SUID includes cases that meet the definition of Sudden Infant Death Syndrome.

Expected Scope of Investigation

The following represents the scope of investigation that may be considered as the "bare minimum" to consider an infant death investigation as "complete:"

- Investigation of the scene where the incidents leading to death are thought to have occurred. The scene investigation should be conducted by a medical examiner or coroner, or a person known to, and acting officially on behalf of the medical examiner or coroner. The scene investigation should be documented in narrative form and augmented with photographs and/or diagrams. Completion of the Sudden Unexpected Infant Death Investigation Report Form, as developed by the CDC,[6] or other similar checklist is considered adequate narrative documentation. Witnesses at

the scene should be interviewed. The original position of the infant when first found unresponsive should be determined as precisely as possible by questioning and written down in detail. Various kinds of demonstrations (such as doll-re-enactment) may be used as a supplemental means of describing the as-found position of the infant, but these methods should not replace proper interviewing.

- A medical history of the infant should be conducted to identify any birth-related problems and to assess the infant's growth, development, immunization history, and medical history. (Preferably, medical records should be used, when available).
- It should be established whether there are any previous unexplained deaths of infant or childhood siblings. If so, relevant details should be obtained. (Preferably, official records should be reviewed).
- It should be established whether there have been previous social service or police contacts or interventions in the home. If so, the details should be obtained. (Preferably, official records should be reviewed).
- A radiograph, even if a single "babygram" view, should be performed. It is clearly recognized that a complete skeletal series is the gold standard. However, in jurisdictions in which this is not an option for financial or technical reasons, a single film will at least provide a radiographic record of gross findings.
- An autopsy should be performed. The autopsy examination should involve in-situ examination of the brain, neck structures, and thoraco-abdominal organs with subsequent removal and dissection. At a minimum, if there is no gross or toxicological cause of death, microscopic examination should be conducted on the brain and meninges, heart, lungs, airways (for example, epiglottis, trachea, bronchi), and liver. If not examined microscopically, stock tissue or paraffin blocks should be taken. Sampled tissues may include kidney, spleen, thymus, bone or costochondral junction, endocrine organs, and representative sections of the gastrointestinal tract. At a minimum, the weights of the brain, heart, lungs, liver, kidneys, thymus, and spleen are recorded. Blood and urine should be collected. If scene investigation, history, or autopsy suggests exposure to drugs (illicit, prescription, over-the-counter, or of a home-remedy nature), toxicology should be performed to evaluate suspected drugs. As a routine, a screen should be conducted to rule out ethanol and major classes of sedatives and stimulants (including cold medications, if being used) that may have caused or contributed to the death. Salicylates, acetaminophen, and carboxyhemoglobin may be tested as indicated by case-specific information.
- Vitreous should be collected for possible use as an adjunct to toxicology testing, or if metabolic or hydration status is an issue. Care must be taken not to compromise internal eye examination for retinal hemorrhages, if required.
- A DNA sample should be archived for genetic testing, if indicated.

- Metabolic screening results should be determined from the medical birth record. A blood spot card should be prepared and retained in case autopsy findings suggest a metabolic disorder such as fatty acid oxidation disorder. If the liver is fatty and birth screening results are not available, the blood should be tested for common fatty acid oxidation disorders such as Medium chain Acyl-CoA Dehydrogenase Deficiency.

Critical General Investigative Questions

The initial investigation should be geared toward answering the questions, or addressing the issues as shown below. The goal of this process is to provide the pathologist with meaningful information relevant to the cause and manner of death, and to guide the pathologist in case management and decision making.

As time and information sources permit, specially trained investigators should collect the information needed to complete the SUIDIRF, and the SUIDIRF should be completed.

Key Issues in SIDS-like Cases

Indicate whether preliminary investigation suggests any of the following:

Yes	No	Issue
		Cause of death due to natural causes—Not SIDS
		Death due to trauma (injury), poisoning, or intoxication
		Asphyxia due to such causes as overlaying, wedging, choking, obstruction of nose or mouth, re-breathing, neck compression, immersion in water
		Environmental hazards such as carbon monoxide, noxious gases, chemicals, sprays, electricity, devices operating in area, licit or illicit drug exposures, habitual exposure to cigarette smoking
		Bed-sharing with other people or animals on any surface
		Unsafe sleeping surface or sleeping conditions
		Acute change in sleep position (placed in different position or place than usual) or diet (introduction of new food type)
		Religious, cultural, or ethnic home remedies or treatments
		Hyper- or hypothermia from hot or cold environment
		Hyperthermia from excessive blanketing, clothing, or wrapping
		Previous acute life threatening events (ALTEs)
		Recurrent visits to medical care facilities without a diagnosis being made
		Recent falls or injury
		Prior deaths of siblings
		Previous encounters with police or social service agencies
		Suspicious circumstances or questionable witness accounts
		Resuscitation or agonal (pre-terminal) medical treatment
		Request for organ or tissue donation
		Objection to autopsy
		Other alerts for pathologist's attention

Any “Yes” answers should be explained and detailed. All of the above information, including the written narrative of reported circumstances, should be available to the pathologist prior to autopsy.

Critical Specific Investigative Questions

In addition to addressing the Critical General Investigative Questions above, there are specific questions that also should be answered early in the investigation and prior to autopsy. In general, these questions would be asked of the “First Responder” which typically would be the person who discovered the infant dead or unresponsive and usually, will be the primary caregiver. However, the answers to these questions may need to be obtained from more than one person.

These critical questions are:

- When was the baby put down to sleep?
    - Approximate Time?
- In what position was the baby put down?
- Who found the baby?
- Did you hear or check on the baby during the interim
- In what position was the baby found?
- Where was the baby when found?
- Was this the baby’s usual sleeping place?
- What was the surface like where the baby was found?
- Was anything covering the baby’s nose and mouth?
- Was there blood or frothy fluid on the baby’s nose and/or mouth?
- Was anyone else sleeping with the baby?
    - Names of the persons, along with age of persons, and estimates of weights and mental status (i.e., were they compromised by alcohol or drugs?)
- Was the room extremely hot or cold?
- Did you notice any fluids on the bedding?
- Was there evidence of wedging?
- What was the baby wearing?
- How many blankets were over the baby?
- What was the general appearance of the residence?
- Did the mother smoke during pregnancy?
- Did any other baby die in the family?
- When was the baby last fed?
- Was the baby ill or on any medication?

Cause of Death Reporting

If properly conducted investigation and autopsy disclose findings (actually, lack of findings) that are consistent with the definition of Sudden Infant Death Syndrome, it is recommended to report the cause of death in Part I of the cause-of-death statement on the Death Certificate as follows:

- Sudden Unexplained Infant Death

Recognizing their similarity, the four statements below are acceptable options for expressing the cause-of-death opinion.

- Sudden death during infancy: no identifiable cause
- Consistent with the definition of Sudden Infant Death Syndrome
- Consistent with Sudden Infant Death Syndrome
- Sudden Infant Death Syndrome

The *manner of death* may be classified as Undetermined or Natural. Any combination of any one of the four choices above and either manner of death will result in the death being officially coded to R95, Sudden Infant Death Syndrome.

The "Undetermined" manner classification is recommended to acknowledge that the true nature of the death is not known, and the following format is suggested:

Part I	A. Sudden Unexplained Infant Death	
	Due to, or as a consequence of: B.	
	Due to, or as a consequence of: C.	
	Due to, or as a consequence of: D.	
Part II	OTHER SIGNIFICANT CONDITIONS: Conditions contributing to death but not resulting in the underlying cause of death in Part I	
Manner of Death Undetermined		Describe How Injury Occurred Undetermined if external causes were involved.

In the example above, the words "Consistent with Sudden Infant Death Syndrome," or "Sudden Infant Death Syndrome" are also acceptable, if preferred.

If the death certificate requires that the date, time, place, and address of injury be completed when the manner of death is classified as Undetermined, the dates

and times may be qualified as “found;” the place may be stated in terms such as “Found at Home.” The location of injury would include the address where the infant was when it was discovered dead or unresponsive.

If a condition such as bed sharing (which could be a stressor or possible external cause of death) needs to be reported on the death certificate, the following format is preferred and recommended:

Part I	A. Sudden Unexplained Infant Death	
	Due to, or as a consequence of: B.	
	Due to, or as a consequence of: C.	
	Due to, or as a consequence of: D.	
Part II	OTHER SIGNIFICANT CONDITIONS: Conditions contributing to death but not resulting in the underlying cause of death in Part I	
Manner of Death Undetermined		Describe How Injury Occurred Undetermined if external causes were involved. Bedsharing with 2 adults

This format is also acceptable:

Part I	A. Sudden Unexplained Infant Death	
	Due to, or as a consequence of: B.	
	Due to, or as a consequence of: C.	
	Due to, or as a consequence of: D.	
Part II	OTHER SIGNIFICANT CONDITIONS: Conditions contributing to death but not resulting in the underlying cause of death in Part I Bedsharing with 2 adults.	
Manner of Death Undetermined		Describe How Injury Occurred Undetermined if external causes were involved.

Placement of the “stressor” in Part II may be construed by some as meaning that it is the certifier’s opinion that bed sharing (or any other condition in Part II) specifically *caused* the death, because that is the way the heading in the Part II

box is worded. An option would be to report Part II stressors such as “Risk Factor: Bed sharing with 2 adults.”

A third method is:

Part I	A. Sudden Unexplained Infant Death associated with bedsharing with adults	
	Due to, or as a consequence of: B.	
	Due to, or as a consequence of: C.	
	Due to, or as a consequence of: D.	
Part II	OTHER SIGNIFICANT CONDITIONS: Conditions contributing to death but not resulting in the underlying cause of death in Part I	
Manner of Death Undetermined		Describe How Injury Occurred Undetermined if external causes were involved.

However, to allow sufficient room for details and explanations, the first option is preferred:

Part I	A. Sudden Unexplained Infant Death	
	Due to, or as a consequence of: B.	
	Due to, or as a consequence of: C.	
	Due to, or as a consequence of: D.	
Part II	OTHER SIGNIFICANT CONDITIONS: Conditions contributing to death but not resulting in the underlying cause of death in Part I	
Manner of Death Undetermined		Describe How Injury Occurred Undetermined if external causes were involved. Bedsharing with 2 adults.

If, for some reason, it is necessary to certify an infant death but a critical element (as defined in this W*hite Paper*) of the investigation is lacking, the following cause-of-death statement format is recommended:

Part I	A. Unclassified Infant Death	
	Due to, or as a consequence of: B.	
	Due to, or as a consequence of: C.	
	Due to, or as a consequence of: D.	
Part II	OTHER SIGNIFICANT CONDITIONS: Conditions contributing to death but not resulting in the underlying cause of death in Part I	
Manner of Death Undetermined		Describe How Injury Occurred Undetermined if external causes were involved. Found dead in bassinette. No autopsy performed.

If investigation and autopsy discloses that death was not consistent with the concept of Sudden Infant Death Syndrome yet no cause of death has been definitively established, the following format is recommended for the cause-of-death statement:

Part I	A. Unexpected and Undetermined Cause	
	Due to, or as a consequence of: B.	
	Due to, or as a consequence of: C.	
	Due to, or as a consequence of: D.	
Part II	OTHER SIGNIFICANT CONDITIONS: Conditions contributing to death but not resulting in the underlying cause of death in Part I	
Manner of Death Undetermined		Describe How Injury Occurred **Undetermined if external causes were involved. Cause of death undetermined after complete investigation.**

Reporting of Possible Stressors, External Causes, or Gray Zone Findings

A “gray zone” finding is a disease condition, possible stressor, or possible external condition that may have contributed to death but for which cause and effect relationship are difficult to establish or rule out.

If a gray zone disease condition is encountered, it is recommended that the condition be reported in Part II of the cause-of-death statement as shown below:

Part I	A. Sudden Unexplained Infant Death	
	Due to, or as a consequence of: B.	
	Due to, or as a consequence of: C.	
	Due to, or as a consequence of: D.	
Part II	OTHER SIGNIFICANT CONDITIONS: Conditions contributing to death but not resulting in the underlying cause of death in Part I Focal bronchiolitis	
Manner of Death Undetermined		Describe How Injury Occurred Undetermined if external causes were involved.

If the gray zone finding consists of an external condition or other finding such as a previous unexplained death of an infant sibling, it is recommend that these conditions be reported in the “Describe How Injury Occurred” box as outlined in the examples on Pages 8 and 9.

It is recommended that the following conditions, if present in a specific case, be reported on the death certificate:

- Bedsharing
- Unsafe or soft sleep surface (if found face down)
- Previous unexplained infant death of sibling
- Excessive blanketing or wrapping
- Face down position when found
- Intoxication (defined as detection of a substance in infant’s system)
- Prenatal exposure to tobacco smoke
- Abrupt change in sleep position
- Abrupt change in sleep location
- Abrupt change in sleep surface
- Injuries of unknown significance (specifying the type)

Data and Other Issues

In the future, it may well be that information about possible stressors or external causes may be collected via reporting systems that are independent from, but parallel to the death certificate. At present, however, there is no official system in place to collect such information. Thus, until such a system is developed, it is reasonable to report possible stressors or external causes on the death certificate as described in this *white paper*.

As of 2003, the National Center for Health Statistics (NCHS) , which processes death certificate information provided by the states, has been collecting the literal text of all entries in the cause-of-death section of the death certificate. NCHS is also considering the development of specific codes for the various stressors and risk factors such as those listed above. If that were to be done, the codes for the various stressors could be attached to the primary ICD code for the cause of death (usually, R95 Sudden Infant Death Syndrome). Using such a system, unexplained infant deaths could then be lumped or split based on the type of conditions reported. Further, using the methods described in this *white paper* will allow separation of infant deaths with inadequate investigation and those infant deaths which, after complete investigation, have no defined cause but are not consistent with Sudden Infant Death Syndrome.

The extent of investigation described in this *white paper* is intended to define a minimum level of investigation. Exceeding the procedures outlined may be needed in some cases and may, in fact, be advantageous on a routine basis. For example, the collection of nasal swabs for respiratory tract viral pathogens may be done routinely in some settings, or on as as-needed basis as suggested by the clinical history and circumstances.

It is conceivable that, with some additional capacity in the future, NAME could function as a storehouse for data related to sudden unexplained infant deaths. It could then share its data with researchers and governmental agencies. Such a system could serve as a “parallel” data system as discussed above.

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