# The importance of a forensics investigation of sudden infant death syndrome: recommendations for developing, low and middle income countries

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## Introduction

One of the most challenging types of death investigation conducted by the Medical Examiners/Coroners (ME/C) Office and law enforcement agency involves the sudden and unexpected death of a previously nor-

Sudden infant deaths syndrome (SIDS), the sudden and unexpected death of a normal and healthy infant, has remained a medical and forensic mystery. Despite years of research all attempts to ascertain the exact cause and manner of death have failed. The information collected during the course of the comprehensive investigation by the various investigation agencies and analysis of the data has not been in vain. The epidemiological, demographic, and pathological data have identified distinctive features and risk factors associated with infants that died from SIDS. Epidemiological data has provided the unique characteristics of infants that died of SIDS that differentiates them from non-SIDS infants. Analysis of information from the death scene investigation has identified key risk factor behaviour associated with SIDS, namely the prone sleeping position. Pathological examination of the internal organs, specifically the brain, has shown some differences between SIDS and non-SIDS infants. However, to gain a complete picture of SIDS data, all countries around the world must provide information, even basic information, to understand this syndrome better. Developing countries must understand their role and importance in developing plans to investigate, collect, and disseminate SIDS data to the rest of the world. This paper provides general guidelines for the investigation of SIDS in developing countries.

Key words: Sudden infant deaths syndrome, SIDS, Death investigation, Forensics, Developing countries.

mal and healthy infant. These deaths are generally classified as Sudden infant death syndrome (SIDS). Typically, a previously healthy infant is discovered dead by the parents during the morning hours. These cases are challenging, not only because of the high emotional cost to the family but also the intense level of investigation required by both the forensic and the law enforcement agencies. The most distressing part of the investigations is the end-result, because it fails to provide to all parties involved a clear and identifiable cause and manner of death. The thoroughness of the death investigation and the accuracy of the information obtained are critical, not only for the local authorities conducting the investigation, but also for the medical, forensic, legal, and public health community at large. The information gathered from the various phases of the investigation includes anatomical data, past medical history (PMH) of the infant and mother, and the circumstances surrounding the death, which must be collected, analyzed and disseminated. This data must become available to the forensic, medical, and public health communities, as well as the general population. Information is critical to furthering our understanding of SIDS and possibly provide an explanation for these deaths. Our understanding of the SIDS phenomenon is directly related to the data collected during the death investigation conducted by the ME/C office and supplemented by reports by the medical response teams, hospital records and the police investigation. SIDS occurs in all countries around the world. Countries such as the U.S. have sophisticated forensic death investigation protocols, standardized data collection forms (1) and highly trained forensic epidemiologists that collect, analysis, summarise, and disseminate SIDS information. In developing countries, such as Bosnia and Herzegovina, issues relating to the economy, internal conflicts, manpower issues, and the availability of specially trained personnel and equipment can greatly impact the level of investigation and the type of information gathering relating to SIDS deaths. An examination of international data on SIDS has revealed that Bosnia and Herzegovina did not provide even basic data regarding SIDS.

In Bosnia and Herzegovina the infant mortality rate is estimated at 21.05 deaths/1,000 live births (2) and according to the United Nations World Population Prospects report, for 2005-2010 (3), and the CIA World Fact book (4) this rate is similar to that of Libya (21.05/1000).

Developing countries should attempt to provide at least minimum, basic epidemiological information such as the total number of SIDS deaths and a breakdown by age, sex, and race. The estimated population of Bosnia and Herzegovina of 3.8 million is unique in one respect that its population is almost entirely white. This is important because it eliminates one of the major known risk factors for SIDS, which is being black (5).

The purpose of this paper is to underscore the importance of each aspect of the infant death investigation and provide general guidelines for developing countries in the investigation of SIDS deaths. This paper will also provide guidelines on the basic types of information that must be collected during the various phases of the death scene investigation, the requirements and importance of a complete post-mortem examination, how forensic epidemiologists have used the collected data to identify risk factors for SIDS, and some possible causes of the syndrome.

## Definition

It is important to start with a clear definition of what constitutes an infant that died of SIDS. The initial definition of SIDS has gone thorough a great deal of fine-tuning since it was first used in 1969 (6). In 1989, the National Institute of Child Health and Human Development defined SIDS as: (1) the sudden and unexpected death of an infant under one year of age who was relatively healthy prior to death; (2) whose death remains unexplained even after the performance of a complete post mortem examination, including toxicological and genetic testing; (3) after the conduct of a thorough death scene investigation; and (4) a review of the infant's and mother medical history (7).

Listing the diagnosis of SIDS as the immediate cause of death on the death certificate (DC) can only be used if all the above conditions have been met. A diagnosis of SIDS is one of exclusion; therefore, only after all other possible causes have been investigated and eliminated should the medical examiner or coroner office conducting the investigation issue the cause of death as SIDS. There is some doubt regarding the appropriateness of using SIDS as the cause of death. The vast majority of SIDS deaths are classified with the immediate cause of death as SIDS and the Manner as Natural. However, others make an agreement for listing the cause of death as Undetermined and the manner of death as Could Not be Determined or Undetermined (8). Developing countries should create a national protocol detailing how all forensic pathologists should complete the DC of infants that died of SIDS. This will ensure consistently and provide a clear method to ascertain an accurate profile of the nation's SIDS mortality rates. SIDS deaths in older literature were referred to as "Crib Deaths" or "Cot Death" because the deaths typically occurred in the crib or cot (9).

Recently, the term Sudden Unexpected Death in Infants (SUDI) has emerged. It is a broad definition, which initially encompasses all infants that died suddenly and unexpectedly. Early in the investigation, the results of histology, microbiology, toxicology and the multi-professional reviews are incomplete, therefore the use of SUDI on the DC is appropriate. After all the various investigations are complete, the immediate cause of death should be changed to either the identified cause of death or, if all the findings are negative, the DC should be changed to SIDS (10).

#### **First responders**

The majority of SIDS infants are discovered either unresponsive or dead within the residence, resulting in a call for medical assistance. The first non-family individuals to interact with the infants are typically "first responders". Depending on the location, first responders consist of either Emergency Medical Technicians (EMT), paramedics, firefighters, or the police. The information they collect, practically their assessment of the infant's presentation and environment, can be critically important to the ensuing investigation.

In the case of an infant, the information provided by the parents or caregivers (babysitter) to the first responder, especially a detailed description of what position the infant was placed to sleep, the position and appearance upon discovery and the general sleeping environment, is important to the investigation. Statements given to the first responders are typically more accurate then those provided later to the police and to the death investigators from the ME/C office. For instance, a mother may have placed the infant on its stomach to sleep but knows that it is safer to place the infant on its back. Therefore, later when the parents are questioned by death investigators from the ME/C office they may provide statements that are inaccurate regarding the circumstances surrounding the events leading to the death. First responders must also note the general condition of the residence, with special attention given to where the infant was discovered and the position it was said to have been discovered in. Often the death scene has been altered by the time death investigators arrive at the residence, which can be several hours or even days after the death occurred.

The question, "What should EMTs or paramedics do if they encounter a clearly dead infant at a residence?" In the old days, EMT and paramedics were instructed to conduct a 'scoop and run' operation especially if it involved an unresponsive infant. Today, with advances in training and equipment, more time is spent to assess, treat, and stabilize the patient at the scene prior to transport to the hospital (11). While each first responder station has its own individual protocol if the infant is clearly beyond medical intervention, all attempts should be made to place the infant back in the original position as discovered and prevent the parents from changing or altering the death scene. First responders must then immediately call the ME/C office and police to the scene. Once the police arrive, the security of the scene is transferred from the first responders to the police until investigators from the ME/C arrive and take jurisdiction of the scene and the investigation (11).

Developing countries must establish clear national guidelines when first responders encounter a deceased infant. As part of their training, they should be instructed on securing a death scene and informing the parents about the role and activities that will be conducted by the ME/C and police. In addition, standardized report forms for first responders should be developed to ensure that all relevant information is collected in a uniform manner which would result in easier analyses. The report should include the following information: the time the call for emergency medical assistance was made, the time of arrival at the scene, assessment of the infant, action taken by medical responders, and statements made as to the events leading to the emergency call.

## The scene investigation

When an infant is declared dead, either by the EMT/paramedics at the residence or by a physician at the hospital, the death investigation begins. Two investigations are conducted simultaneously: one by the police and one by the medical examiners/coroners office. When a death occurs at a residence, the emergency call for medical assistance also results in a response by police. In the U.S. the ME/C office has jurisdiction of the death scene, however, this authority may vary country by country (11). A clear chain of command must be firmly established between law enforcement and the ME/C office as early as possible. At this phase of the investigation, the two investigation teams (law enforcement and ME/C) are both attempting to ascertain a history of the circumstances that occurred prior to the discovery of the deceased infant.

# **Police investigation**

The police investigation involves questioning those that interacted with the infant prior to the incident, taking statements on the role and actions taken by each individual, and obtaining a detailed narrative of the circumstances immediately surrounding the discovery of the infant. The involvement of the police, especially at the beginning of the investigation, may alarm parents who have just suffered a loss (10). The police must make it clear, and with sensitivity, that they must conduct an investigation when the death is sudden and unexpected, and it is simply part of their overall duties and part of the standard protocol. While the death of an infant is initially suspicious the police should refrain from surrounding the home with police tape and handcuffing the parents. The axiom that it is a crime scene until proven otherwise should be adhered to in most cases, but some adjustment should be considered in the case involving the death of an infant. It is a death scene, therefore, the infant's room and the location where the infant was discovered should be secured until the forensic investigators arrive to take photographs and collect forensic evidence. Current police training in criminal investigations emphasizes the importance of 'the golden hour' - the first hour of evidence gathering that produces crucial evidence before it can be lost or contaminated. During this phase, the parents should be taken to

another part of the house and questioned by the police. If evidence such as the bedding (crib), mattresses, or sheets have to be removed the parents should be informed that they will be returned after the investigation. Police officers investigating these types of cases should be educated in the fact that the vast majority of babies' deaths are from natural causes. However, suspicion should arise only if there is material evidence of something irregular, such as medical evidence of injury or records of previous interaction with social services, Child protection units, or the police. The police will also question relatives and neighbours regarding the behaviour and activities of the family members (10).

In a death involving an infant, the police may be hesitant to conduct intensive questioning of the parents, as they would do if the victim were a middle aged male. The detectives may find it hard to accept that parents are capable of murdering or even harming their own children. In addition, they do not wish to conduct an aggressively interrogation of the parents as if they were murderers without any forensic evidence or visible trauma to the infant to warrant such an integration. Law enforcement offices conducting this type of investigation must however be aware that mothers are capable of harming their infants due to a condition called Munchausen's by Proxy and these infants deaths have been incorrectly classified as SIDS (12).

In developing countries, it may not be practical to educate and train all the detectives of the nation's police force in the proper methods to investigation a SIDS or possible SIDS deaths. Therefore, a small number of detectives in each region should receive special training on how to handle such cases and be assigned to these types of deaths when they occur.

#### Forensic investigation

The forensic medico-legal investigation is conducted by the ME/C office and is com-

posed of three main sections: (1) Death Scene Investigation, (2) Autopsy and Toxicology, and (3) Review of the Past Medical History of the Infant and Mother. The ME/C investigation begins at the death scene by taking photographs of the overall residence then numerous images of the location and bedding where the infant was discovered. The investigators attempt to obtain an accurate representation of the events immediately prior to the death. Their examination focuses on three key factors: (1) the infant, (2) the sleeping location, and (3) the infant's environment. Critical information to be collected regarding the infant includes the time and method of the last feeding (breast or bottle), the time and position the infant was put down to sleep, and the time and position it was discovered. Anatomically correct dolls can be used to recreate the events leading up to the discovery (13). Next, the infant's sleeping location is examination in great detail. The crib is examined for general condition, the size and firmness of the mattress, and the number of covers and items within the crib are also noted. If the infant was sleeping in something other than a crib, that sleeping surface is photographed and described in detail. Information collected about the infant's environment should include the temperature of the infant's room and a search for possible sources of gas, carbon monoxide, carbon dioxide or other toxic gases. Air samples should be taken for future analysis. The parents' smoking habits, alcohol and drug use should be noted.

The level of training, experience, and equipment possessed by the ME/C death investigators affects the depth and level of detail of the information collected at the death scene. Death investigators in developing countries can gain additional training by enrolling in online classes offered by the FBI and CDC. Hands-on experience can be obtained by participating in exchange programs with countries like the U.S., Great Britain, or Australia. In these programs, the foreign death investigators are exposed to the procedures and techniques used to investigate a SIDS death in the U.S. or another country. One of the most basic and important types of equipment that all death investigators should obtain is a digital camera. They have become extremely easy to operate, are inexpensive, and critically important if the case goes to trial.

#### Examination of the infant

After pronouncement of the death of the infant, it is then transported from the residence or hospital to the morgue. The infant will first be photographed as it arrived from the scene, then the clothing is removed and examined for trace evidence. The infant will then first undergo an external examination. This part of the examination looks for any signs of recent and remote injuries and/or trauma. The external examination may provide forensic evidence that will either support or call into question statements made by the parents. Changes after death such as rigor mortis and livor mortis may indicate clues to the infants' final position after death. This information should be carefully compared to the information provided by the parents. In addition, if evidence of recent or remote blunt forced trauma is identified, the parents must be questioned by the police and ME/C office about the possible etiology of these injuries. Complete radiographic images of the infant should also be taken and evaluated by a trained paediatric radiologist.

Next, the internal organs are examined using the standard "Y" shaped evisceration methodology followed by removal of the brain. The organs are examined in-situ first then removed, weighed and examined grossly and microscopically. A forensic pathologist should conduct the examination and the police officer or detective handling the investigation should be present during the forensic autopsy. Samples of each internal organ should be sent to the histology department, where microscopic slides are prepared. The ME/C office should save small samples of all the internal organs in formaldehyde for at least 5 years and the histological slides indefinitely. Where possible, these materials should be made available to research centres for study.

A complete forensic autopsy is critical because the diagnosis of SIDS requires that the post-mortem examination has been conducted and the results have failed to demonstrate a clear cause of death (8). The forensic examination typically does find some non-specific findings, such as upper respiratory infection and petechiae hemorrhage (14). Because the results of the SIDS autopsy are negative, a number of ME/C offices may choose not to perform one. Forensic pathologists that refuse to conduct an internal examination often offer the justification that they do not want to put the family through such an examination. This action in fact constitutes a disservice to the family, the medical community, and to those studying the syndrome. By refusing to perform a complete examination, diseases or conditions may be missed that can affect the mother's future children. Technically an infant that did not undergo an internal examination cannot be signed out on the DC as SIDS. The cause of death and manner of death must both be listed as Undetermined. This type of DC would cause additional stress and confusion for the family.

## Toxicology/Genetic screening

A part of the complete internal examination includes the collection of various body fluids (blood, bile, urine, eye fluid, and CSF). Blood samples should be taken from a venous or arterial site (e.g. femoral vein). Cardiac puncture should be avoided as this may cause damage to intrathoracic structures and make post-mortem findings difficult to interpret. Blood serum and urine should be sent to a forensic toxicologist for toxicology analysis for the presence of poisons and drugs. Blood cultures should be tested for microbiology cultures (aerobic and anaerobic). Cerebrospinal fluid (CSF) should undergo culture screening. Blood should be sent, ideally on a Guthrie card, for genetic screening (10). This screening should included markers for underlying metabolic diseases such as Medium chain acvl CoA dehydrogenase deficiency, or MCAD. MCAD is the most frequently metabolic disorder associated with SIDS. This screening is also important for the surviving siblings of SIDS, in order to prevent the tragedy of recurrent SIDS in some families (15).

A medico-legal system must be established in developing countries, either as a medical examiner or coroner system. In smaller countries, such as Bosnia and Herzegovina, a centralized system with one main ME/C office and a number of smaller satellite offices maybe the most economical. In order to gain experience and consistency, one or a small group of forensic pathologists should examine all sudden and unexpected infant deaths in the country. They should establish standard protocols so that all infants that die suddenly and unexpectedly undergo a through post-mortem examination. In developing countries, nurses and physicians should receive training regarding SIDS, and the importance and the need for a forensic investigation and autopsy. The establishment of a Child death review team. discussed later, will ensure that all infants receive a proper and correct investigation.

# Past medical history of infant and mother

One of the functions of the ME/C office is to ascertain and review the past medical history of the mother and infant. Regarding the

mother the following information should be abstracted from the medical records: age of each pregnancy, the interval between each pregnancy, number of pre-natal visits, and the use of drugs and tobacco during the pregnancy. Information collected about the delivery should include length of gestation, type of delivery, complications associated with the delivery, APGAR scores, and the birth weight and height of the infant. The medical history collected on the infant should also include growth history, number of post-natal visits, vaccination history, medications, and health immediately prior to death. The ME/C office has the authority to subpoena the mother's and infant's medical history from the birth hospital for review. The ME/C office should establish a good working relationship with the area hospitals to ensure that all relevant medical records are turned over to the ME/C office.

# Child death review

Child death review teams (CDRT) can be organized at local, regional, or state level. They are designed to conduct retrospective reviews of all deaths under the age of 18 years that occur within that team's jurisdiction. The role of CDRT is to ensure that a thorough and complete investigation is conducted. The CDRT is a multidisciplinary team composed of the following individuals: first responders (ambulance and fire personnel), law enforcement officers, medical examiners/coroners officers, forensic epidemiologist, prosecutors, child protective service, paediatricians, emergency room personnel, and representatives from the school district. The objective of a CDRT is to ensure that all the available information from the different disciplines is presented and reviewed. In addition, it assists in creating an accurate portrait of the history of the child's death and ensures a consensus regarding the listed cause and manner of death. The end-result

of the CDRT is four-fold: first, the collection of epidemiological, demographic, and statistical data; second, the publication of monthly and yearly mortality reports; third, the suggestion of ways to improve the methodological investigation of infant/child deaths; and finally, to make recommendations to prevent future infant/child deaths (16).

CDRT have been operating in a number of states within the U.S. and a few developed countries. Developing countries should implement the creation of CDRT to provide a review of the thoroughness and completeness of these investigations. During the early phases of the development of a CDRT, there should be monthly meetings between the ME/C and law enforcement agencies to review methods and discuss ways to improve their joint investigation. In the early stages of the CDRT, they should initially concentrate on compiling basic epidemiological, statistical, and circumstantial data relating to SIDS deaths. Over time, other members should be added to the team.

#### **End-results of SIDS investigations**

All phases of the death investigation are important and provide, and will continue to provide, valuable information for our understanding of SIDS. The end result of years of collecting and examining large amounts of detailed epidemiological, anatomical data, and the features of the circumstances surrounding the deaths from around the world has resulted in a number of discoveries.

First, it clearly illustrated the unique epidemiological and demographic features of SIDS that differentiates it from other deaths during the post and perinatal period. Second, it identified risk factors associated with SIDS. Specific risks associated with SIDS include: being male, black, the prone sleeping position, excessive layers of clothing, and exposure to second hand smoke (11).

Based on the forensic epidemiological investigation of the data, the following fea-

tures have been reported: (1) a unique death distribution with the majority of deaths occurring between 2-5 months of age, (2) a greater number of deaths during the winter months, (3) a higher death rate among black and male infants, (4) mothers are typically young, unmarried, of limited education, frequently use drugs and smoke, and of lower socioeconomic status (5). Environmental risk factors shown to be associated with SIDS include soft bedding, co-sleeping (bed sharing), and over-wrapping (17).

One of the most important discoveries was the risk associated with the prone sleeping position and SIDS. Based on epidemiological data analysis of the information from the death scene investigation, the majority of infants that died of SIDS where discovered in the prone sleeping position which led the National Institute of Child Health and Human Development in 1994 to initiate the "Back to Sleep" campaign in the United States. The campaign resulted in a dramatic decline in the incidence of SIDS in the U.S. (18) and other countries where the program was implemented.

Whereas the main function of the forensic autopsy is foremost the exclusion of identifiable diseases, identification of congenital conditions, and the discovery of trauma it has a second purpose for research. The examination of saved tissue samples and blood recovered from these infants will allow for detailed examination by researchers attempting to discover the possible cause of SIDS. The examination of brain tissue has shown some anatomical differences between SIDS and non-SIDS infants. Recent studies have shown that SIDS brains have fewer CO receptors (17). DNA samples can be used to search for genetic makers for SIDS (17). To date however, genetic analysis has not located any specific genotype differences that differentiate infants who die of SIDS that can be linked to specific clinically defined phenotypes (19). However, several differences

Death Scene Investigation	Secure Death Scene Location
	Separate Infant and Parents
	Photo-document the Scene and Infant
	Conduct Witness Interviews (Parents/Care Givers)
	Re-enactment of the discovery of the infant (use dolls)
	Collect Atmospheric Air Samples
	Remove infant and other critical evidence
	Prepare Death Investigation Reports
Pre-Autopsy Review	Obtain and Review Infant's Past Medical Records
	Obtain and Review Mother's Past Medical Records
	Review Death Investigation Case Information
	Review First Responder Reports
	Review Police Reports
External Examination	1. Photograph Infant
	2. Establish Infant Growth and Development Parameters
	3. Document all signs of recent and remote trauma
Internal Examination	Gross Examination of Internal Organs
	Remove/Weight Internal Organs including the brain
	Microscopic Examination of Organs
	Collect Body Fluids: Blood, Bile, Urine, Eye Fluids
	Conduct Toxicological Analysis
	Conduct Microbiology/Genetic Screening
	Save representative samples of tissues
Post Examination Actives	Collection of Epidemiological Data
	Collection of Anatomical Data
	Collection of Pathological Data
	Dissemination of SIDS Information
	Publication of Case Reports
	Conduct Retrospective Studies

Table 1 Standard Protocol for Sudden infant death syndrome Investigation

have been noted in gene polymorphisms among SIDS infants involving the sodium channel (SCN5A), potassium channel, and serotonin transport (5-HTT) genes (20, 21). Other polymorphisms have also identified genes that affect the autonomic nervous system development (PHOX2a, RET, ECE1, TLX3, EN1) (22) and the anti-inflammatory cytokines interleukin (IL-10) (23). The ME/C offices should freeze a small sample of blood from SIDS and non-SIDS cases for future comparison and research. This blood should be stored in a -70 freezer. Table 1 illustrates the standard protocol for the investigation of Sudden infant death syndrome. This table should be reproduced and provided to forensic death investigators and forensic pathologists and laminated copies should

be posted in mortuaries around the county as an operating guide to the steps involved in a SIDS investigation.

## Conclusions

The analysis of the information collected from various types of investigation of SIDS infants has resulted in the identification of a number of risk factors that have been associated with the phenomenon. The association of the sleeping position coupled with education campaigns has resulted in an overall decrease in the total number of SIDS deaths. However, the aetiology of the cause of these deaths has still not been ascertained. Those investigating these types of death, typically the ME/C, must go beyond their primary function of determining the cause and manner of death and play a more active role in the collection of epidemiological, demographical, anatomical, and physiological information must be meticulously collected. In addition, biological specimens should be available for researcher centres. All countries, even developing ones must play an active role in the investigation of SIDS deaths. They must begin with a through investigation of the death scene and conduct a complete autopsy of the body. In addition, they must provide the results of their findings to the world's researchers. The ME/C office has a responsibility, not only to the infants' families to conduct this type of investigation, but also to future generations of infants. Developing countries have the advantage of starting with the established protocol, standards, and techniques developed by developed countries as their starting point.

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