SPECIAL COMMUNICATION

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Proceedings of "Workshop on Guidelines for Scene Investigation of Sudden Unexplained Infant Deaths"—July 12–13, 1993

REFERENCE: Iyasu, S., Hanzlick, R., Rowley, D., and Willinger, M., **"Proceedings of 'Workshop on Guidelines for Scene Investigation of Sudden Unexplained Infant Deaths' "** *Journal of Forensic Sciences*, JFSCA, Vol. 39, No. 4, July 1994, pp. 1126–1136.

ABSTRACT: The 1992 Senate Report #102-104 and House Report #102-121 recommended that the Interagency Panel on Sudden Infant Death Syndrome (SIDS) review and establish an updated standard death scene investigation protocol for scene investigation of unexplained infant deaths. As a result of the recommendation, the Centers for Disease Control and Prevention's (CDC) Division of Reproductive Health (DRH), and the National Institute for Child Health and Human Development (NICHD) organized a workshop entitled "Workshop on Guidelines for Scene Investigation of Sudden Unexplained Infant Deaths," which was held in Rockville, Maryland, on July 12–13, 1993. This article outlines the proceedings of the workshop. The goal of the workshop was to gather information and ideas that could be used to establish guidelines which could be useful in developing a model death scene investigation protocol. It was not a goal of this workshop to produce a specific protocol during the workshop. The workshop was successful in generating a variety of information and ideas concerning the desirable attributes of a protocol including essential items of data, identification of certain training needs, specification of procedures for data collection, reporting, and quality assurance, and proposed strategies for implementation. This information can now be considered by the HHS Interagency SIDS Panel to develop specific guidelines for developing a standard scene investigation protocol for sudden unexplained infant deaths.

KEYWORDS: pathology and biology, death investigation, sudden infant death syndrome, death scene investigation, protocols

In 1990, the U.S. Department of Health and Human Service, (HHS) reconvened an Interagency Panel on Sudden Infant Death Syndrome (SIDS) to facilitate communication among the various federal agencies that deal with SIDS-related biomedical research, surveillance, and health service delivery. Table 1 shows the agencies represented on the Panel.

[1] Centers for Disease Control and Prevention, Atlanta, GA.
[2] National Institute of Child Health and Human Development.
Received for publication 4 April, 1994; accepted for publication 18 April 1994.
Presented in part at the annual meeting of the American Academy of Forensic Sciences, San Antonio, Texas, February 18, 1994.

TABLE 1—*Federal interagency SIDS panel participating agencies.*

Centers for Disease Control and Prevention
National Center for Chronic Diseases Prevention and Health Promotion
National Center for Environmental Health
National Center for Health Statistics
National Institutes of Health
National Institute of Child Health and Human Development
National Institute of Drug Abuse
National Institute of Mental Health
National Institute of Neurological Diseases
National Institute of Alcohol Abuse and Alcoholism
National Institute of Deafness and Other Communication Disorders
National Center on Child Abuse and Neglect
Health Resources and Services Administration
Maternal and Child Health Bureau
Consumer Product Safety Commission
Food and Drug Administration
Indian Health Service
Department of Justice
Department of Defense

The 1992 Senate Report #102-104 (page 74) and the House Report #102-121 (pages 51–52) contained language recommending that the Interagency Panel on SIDS review and establish an updated standard death scene investigation protocol for SIDS. The actual text from the reports is as follows:

> "The Committee has learned of the inconsistency throughout the States with respect to standard autopsy and reporting protocol for unexplained infant deaths, or sudden infant death syndrome. To improve upon this situation, the committee recommends that the HHS Interagency SIDS Panel review and establish updated standard death scene protocol for sudden infant death syndrome incidents. The Committee encourages the Interagency Panel to utilize input and advice from medical examiners, coroners, forensic and pediatric pathologists, epidemiologist, experts in the SIDS field, and State jurisdictions that have had success in implementing standard protocols."

As a result of the recommendation, the Centers for Disease Control and Prevention's (CDC) Division of Reproductive Health (DRH), and the National Institute for Child Health and Human Development (NICHD) organized a workshop entitled "Workshop on Guidelines for Scene Investigation of Sudden Unexplained Infant Deaths," which was held in Rockville, Maryland, on July 12–13, 1993.

The goal of the workshop was to gather information and ideas that could be used to establish guidelines which, in turn, could be useful in developing a standard death scene investigation protocol for sudden unexplained infant deaths; it was not a goal of this workshop to produce a specific protocol at the workshop. This is a report of the proceedings of the workshop.

Methods

Consultants with expertise in SIDS and representatives of relevant public and private organizations were identified as prospective participants in accordance with the recommen-

dations in the Senate and House reports. Fifty-seven participants attended the workshop. The participating organizations and representatives are shown in Tables 2 to 4, and the consultants are listed in Table 5.

Participants were provided with information and SIDS literature in advance of the workshop that detailed the background of the House and Senate recommendation and the relevant aspects of SIDS [*1,2*]. A sample list of data items drawn from other existing death scene investigation protocols was also sent to each participant so some thought could be given to data items in advance of the workshop.

Five major topics were developed for discussion:

1) Identification of desirable attributes of a standard scene investigation protocol for sudden infant deaths;
2) Identification of data elements with prioritization as core or optional data items;
3) Identification of training needs;
4) Identification of procedures for data collection, reporting, and quality assurance; and
5) Strategies for implementation.

TABLE 2—*Workshop on SIDS scene protocol participating public health service representatives CDC, FDA, NIH, HRSA, Indian health service.*

Centers for Disease Control and Prevention:
Randy Hanzlick, MD, National Center for Environmental Health
Brenda D. Hayes-Wilson, MPH, DSW, Office of Minority Health
Solomon Iyasu, MBBS, MPH, Division of Reproductive Health
Diane Rowley, MD, MPH, Division of Reproductive Health
Gilberto Chavez, MD, MPH (California Department of Health Services)
George Gay, Division of Vital Statistics
John Kiely, PhD, Division of Analysis
Marian MacDorman, PhD, Division of Vital Statistics
Sam Notzon, PhD, Office of International Statistics
Kenneth Schoendorf, MD, MPH, Division of Analysis

Food and Drug Administration:
Center for Devices and Radiologic Health:
Susan Alpert, PhD, MD
M.S. Gluck, D.Sc.

National Institutes of Health:
National Institutes on Alcohol Abuse and Alcoholism:
Mary C. Dufour, MD, MPH
Laurie Foudin, PhD
National Institute of Mental Health:
Karen H. Bourdon, MA
National Institute of Deafness and Other Communication Disorders:
Howard Hoffman, MA
National Institute on Drug Abuse:
Coryl LaRue Jones, PhD
National Institute of Child Health and Human Development:
Helen Lerner, RNC, EdD.
Marian Willinger, PhD

Health Resources and Services Administration:
Maternal and Child Health Bureau:
Michele Kiely, DrPH
Peter G. Van Dyck, MD, MPH (Healthy Start)

Indian Health Service:
Chris Krogh, MD, MPH

TABLE 3—*Workshop on SIDS scene protocol representatives of other agencies and organizations.*

Private Sector:	
American College of Obstetricians and Gynecologists:	Louise M. Wulff, Sc.D
Health and Medicine Council of Washington:	Dale P. Dirks
Police Executive Research Forum:	Ortwin A. Tony Narr, MA
College of American Pathologists:	Richard C. Forede, MD
American Academy of Forensic Sciences:	William Q. Sturner, MD
International Association of Chiefs of Police:	Thomas J. O'Loughlin, ESQ
National Association of Medical Examiners:[a]	
American Academy of Pediatrics:	Randall C. Alexander, MD
Society for Pediatric Pathology	Kevin E. Bove, MD
Association of State and Territorial Health Officials:	Joye Maureen Carter, MD
State or Federal Government:	
Department of Justice:	Brenda G. Meister
Bureau of Indian Affairs:	Ted Quasala
Department of Defense:	JanaLee Sponberg, DAE
Consumer Product Safety Commission:	Manon A. Boudreault, MPH Paul E. Phillips N. J. Scheers
National Center on Child Abuse and Neglect:	Sally Flanzer, PhD David W. Lloyd, JD

[a] Multiple workshop participants are members of this organzation.

Three break-out groups of approximately 19 persons each, with each group having a moderator and recorder, were established to consider each of the five major topic areas. Each break-out group was asked to "brainstorm" using a "round-robin" method—each participant, in turn, and without interruption or discussion, suggested ideas, and the process continued until ideas were exhausted. Ideas were then *clarified*, if needed, and similar ideas were *combined*, while irrelevant or inappropriate ideas were *eliminated*. Ideas were then *ranked* in order of importance by having the group members vote for the three ideas they felt to be of highest priority. All ideas were recorded. The moderators were instructed in the round robin technique prior to the workshop.

A list of specific issues was provided to each break-out group for discussion. The issues for each major topic were as follows.

TABLE 4—*Workshop on SIDS scene protocol private sector agencies and representatives.*

The American Sudden Infant Death Syndrome Institute:
Alfred Steinschneider, MD, PhD
Kevin Winn, MD
SIDS Alliance:
Thomas Moran
Association of SIDS Program Professionals:
Mary McClain, RN, MS
National SIDS Resources Center:
Olivia J. Cowdrill, MS
Institute for Infant and Child Survival, Inc:.
Denise R. Brooks, MS, RRT
American Bar Association-Center on Children and the Law:
Susan Wells

TABLE 5—*Workshop on SIDS scene protocol consultants.*

James D. Beisner, MPPA (Chief Deputy Coroner)
Chief Deputy Coroner, Orange County, Santa Anna, California
Mary Fran Ernst (Medical Examiner's Investigator)
Medical Examiner's Office, St. Louis, MO
Joseph Halka, MD (Medical Examiner/Forensic Pathologist)
Orange County Forensic Science Center, Santa Anna, CA
Fern Hauck, MD, MS (SIDS Researcher)
Department of Preventive Medicine and Epidemiology, Loyola University Medical Center, Maywood, IL
Gus Kolilus (Investigation and Training Administrator)
Missouri Department of Social Services, Jefferson City, MO
Robert Kirschner, MD (Medical Examiner/Forensic Pathologist)
Office of the Cook County Medical Examiner, Chicago, IL
Henry Krous, MD (Pediatric Pathologist)
Children's Hospital Department of Pathology, San Diego, CA
Patricia McFeeley, MD (Medical Examiner/Forensic Pathologist)
Office of the Medical Investigator, Albuquerque, NM
Brad Randall, MD (Coroner/Forensic Pathologist)
Laboratory of Clinical Medicine, Sioux Falls, SD
John E. Smialek, MD (Medical Examiner/Forensic Pathologist)
Chief Medical Examiner, Baltimore, MD
Marie Valdes-Dapena, BSMD (Pediatric Pathologist)
Department of Pathology, Univ. of Miami School of Medicine

Attributes

a) What are the goals of a death scene investigation protocol for SIDS?

b) Should the protocol be geared primarily toward determination of cause and manner of death or should it address the needs of epidemiologic research? How much weight should be given to each?

c) What qualities should the protocol have to make it practical, useful, and simple to use in virtually any death investigation jurisdiction?

d) Medical versus non-medical content of the questionnaire: how can collection of relevant medical information be assured when the protocol might be used by scene investigators with diverse training backgrounds?

e) How can the protocol satisfy the needs of agencies with an interest in SIDS, but whose responsibilities lie outside the determination of cause and manner of death?

f) How can the needs of families be met?

g) In a specific case, what criteria should be followed to determine when use of the standard scene protocol is indicated? How much of the information should be collected prior to or after the autopsy?

Core Data Elements

a) Sociodemographic information

b) Relevant dates and times of significant events surrounding the death of the infant

c) Observations at the scene

d) Relevant medical history (mother, child, siblings)

e) Information from person who last saw the child alive and the person who first found the child unresponsive

f) Information from emergency medical technicians, police, and other first responders

g) Information from health care providers

h) Information from father, witnesses, and primary caretaker

i) Additional information not included in above categories

Training Needs

a) What options are available to train persons who might use the standard protocol?

b) Is training needed, or should the simplicity of the form preclude a need for training?

c) If training is needed, how should the options of videotapes, printed material, on-site training, instructional conferences, and other options be prioritized?

Data Collection, Reporting, and Quality Assurance

a) Should there be one model form developed for data collection? Should data be collected and maintained as hard copy or should it be computerized?

b) Aside from the local medical examiner or coroner's office, who should receive information collected from the scene?

c) As part of the quality assurance process, how should data collection and reporting be monitored?

d) How should information relevant to the manner and cause of death collected during the scene investigation be reflected in the death certificate?

Implementation

a) How can the protocol be implemented with a minimum of funding, time, manpower needs, and yet still be effective?

b) What incentives might be used to promote use of the standard protocol?

c) Would the protocol be tried on a small scale before it is made generally available?

d) Should endorsements be sought by agencies and organizations concerned with SIDS investigations?

e) Should use be mandated? If so, at what level?

Following each break-out group session, results were reported to the entire group of participants by the appropriate group moderator at a plenary session directed at the specific topic.

Attributes, core data elements, and strategies for implementation were each considered by three break-out groups independently of one another. A single break-out group addressed training needs, and another single break-out group addressed procedures for data collection, reporting, and quality assurance, while a third break-out group was assigned the task of consolidating all suggested data elements into a list of core elements.

Diane Rowley presented a brief overview of SIDS and the background information that led to the House and Senate recommendations and to the organization of the workshop. Marian Willinger oriented the participants to Interagency Panel on SIDS, the features of the SIDS research program at the National Institute for Child Health and Human Development (NICHD) and the meeting site. Randy Hanzlick presented a general summary of death investigation in the United States, particularly as it relates to SIDS, and emphasizing the diversity in systems, laws, and death investigation personnel that might affect the ability to implement a standard scene investigation protocol, while also discussing existing groundwork that might facilitate implementation. Patricia McFeeley gave an overview of SIDS investigation and the international efforts that have been undertaken to develop standard protocols for SIDS investigations. Solomon Iyasu then summarized the procedures and timetable that would be followed during the workshop and clarified the group assignments and group responsibilities.

Following the meeting, information and ideas from the various break-out groups were combined, summarized, and paraphrased by Marian Willinger, Solomon Iyasu, and Randy Hanzlick, using a clarification and combining scheme similar to that used by break-out groups.

A rough draft of this report was sent to workshop participants for their review and comments, which were considered in the preparation of this final report.

Results

Following are the somewhat telegraphic statements derived from the information and ideas provided by the various break-out groups.

Attributes: Goals

The primary goal of the protocol should be to ensure adequate case investigation and the possibility of generating a single reasonable hypothesis as to the cause of death.

The protocol should provide an opportunity for inclusion of any evidence that could be significant. It should help the responsible pathologist, medical examiner, or coroner arrive at a single, logical and accurate decision regarding the cause, manner, and mechanism of death and assist him or her in ruling out other potential causes. The completed protocol should also "raise red flags" if indicated, prompting further investigation.

The protocol should be a practical tool, the use of which will facilitate the collection of standardized information, at the same time assuring the quality of investigation. It should provide information that is helpful to case medico-legal investigators, research workers, and other users. The form should be constructed so that the information derived from its use will serve parents, counselors, and public health agencies; ideally, using it, the public health agencies can detect and warn the public about specific, unsafe health practices. The information should help these agencies in deciding which public health programs to fund. It should serve to identify risk factors, such as those related to consumer products.

Finally, it should be of assistance in validating information related to a given case, but derived from other sources.

Research Emphasis

Ideally, use of a standardized protocol should provide data that are useful for research purposes as well as for the determination of cause of death; however, the main emphasis must be on the latter in every case. Hence, the protocol, should include data that can be employed in addressing epidemiologic questions or in developing research hypotheses. Nevertheless, this process of data collection from scene investigation must be viewed and promoted ultimately as a public health activity rather than as a research endeavor.

Qualities of the Protocol

The protocol should provide a uniform approach to the investigative process. It should be legally sound and enable the collection of unique information not readily available elsewhere.

It should be clear and self-explanatory but should be accompanied by an instruction manual to ensure uniform implementation.

There should be within it "core" data items and "optional" items, and the format should include "decision trees" and "skip patterns" to facilitate the best possible collection of relevant information without being tedious. The protocol should be "user friendly," use clear and simple language, be culture and language sensitive, be manageable by persons with diverse backgrounds, experience, and training, and use common terms and definitions with clearly phrased questions, directed at specific issues. It should be explicit, succinct, relevant, efficient, inclusive, comprehensive, and interdisciplinary.

The protocol should be objective, non-accusatory, sensitive, and non-judgmental. It should provide an opportunity for the inclusion of narrative descriptions, diagrams, and checklists in addition to responses to objective questions. The normal range of values should be provided in the protocol for certain items of information that are measured.

Finally, it should be computer adaptable and electronically transmissible.

Ensuring Collection of Medical Information

The protocol should be simple, using non-medical words whenever possible, and the information should be collected from the most "direct" source (from the child's physician); inclusion of data from medical records should be encouraged.

A minimum of information should be collected initially but the protocol should provide for the possibility of a return visit to the family to ask further questions. It should be designed so that it can be adapted for use in a variety of communities or local settings. Questions must be unambiguous. Use of some checklists will be necessary.

There should be a mechanism for feedback to the various providers of information. Information having to do with the infant's health, garnered at this time, should be contrasted with the parent's notions of their baby's well being before the fatal incident.

Meeting Needs of Agencies

Construction of the protocol should include input from a variety of disciplines including public health personnel and individuals from forensic medicine and provide for feedback to various agencies. The protocol should be comprehensive and easily understood.

The data should be accessible and responsive to possible inquiries yet include safeguards pertaining to confidentiality.

Meeting the Needs of Families

The investigation should be conducted in a timely, professional, and caring manner. The process should be explained to the family beforehand. The amount of information provided to the family should be controlled. Repetition should be minimized.

A variety of specific responses to families should be provided. Providing premature diagnoses to the parents must be avoided, as they may be erroneous when further information becomes available. Members of the family should be given opportunities to express their views as to what happened to their child. The necessity for an autopsy should be explained to them. Use of the protocol should include opportunities for introducing family members to grief counseling programs and/or referral to SIDS groups as indicated. It should provide for the collection of as much information as possible prior to the conduct of the autopsy, at the same time, allowing for the addition of further information following completion of all postmortem studies.

Data Collection

There should be one model in both hard-copy and electronic form. An expanded version should also be available. The form should be transmissible and enable scanning, especially of the narrative portion. The form should be pre-tested and initiation of its routine use carefully timed. There should be in-service training in its use before the program is mounted.

Information Availability

Anyone with a justifiable need for the information on the forms should have access to it but confidentiality must be safeguarded. There should be a means established whereby persons in need of the information on the completed protocols can sign for its release.

At the outset, systems managers must decide ownership of the data and the appropriate use by persons outside of the local medico-legal system. Policies regarding the release of information are probably best determined at the state level. Specific information released should be selected according to specific needs. There should be a federal repository for all of all of the databases.

Reflection of Investigation in Death Certification

There should be some mechanism whereby individual death certificate will reflect whether or not a scene investigation has been conducted or is pending. In addition, there should be (if it does not already exist) a method available to amend the death certificate based upon new information provided by the protocol. Training programs must be established to promote regular use of the standardized scene investigation protocol.

Training

Options

Training should be coordinated with existing training programs; it should be interdisciplinary and involve relevant federal and local programs, professional associations and SIDS support groups. Federal clearing-houses could distribute information about scene investigation, sudden infant death, and child fatality review to local agencies. Existing training programs regarding death scene investigations should be evaluated to determine their appropriateness and adaptability. Legislation should provide funding. An evaluation component should be built into the training program.

Multi-disciplinary composition of the training teams could provide an opportunity for members to learn from one another. Resource and Training Center could be developed including the people and the materials for instruction. Other options for training should include the use of mock cases and on-site training.

Is Training Needed or Can it be Omitted?

Training will be needed and should involve all persons who will be participating in the response, scene investigation, and/or follow-up investigations and procedures. Training should be arranged in phases, be continuous, and conducted by a multi-agency team. It should focus initially on investigators, with further implementation as dictated by local jurisdictions. Within the individual training program special nature of infant death should be emphasized. All investigators need complete understanding of this unique situation including recognition of the fact that investigations a piece of a much larger picture.

Prioritization

The two most important features in the development of the Resource Center would be the following: (1) a set of tailor-made teaching materials, and (2) professional videotapes—including typical discussions between parents and investigators. Other, necessary materials that might be developed include: mock cases, other printed material on-site training.

The energies of existing crusaders in the community should be harnessed. Certification of death scene investigators should be considered. The training program should be evaluated periodically.

Training should concentrate on developing the observational skill of first responders. It should include training in culturally sensitive interviewing techniques. A catalogue of available materials should be made available. Trainees should understand the rationale for each of the questions they are included in the protocol.

Implementation

Minimized Money and Time

It is doubtful that a protocol could be implemented successfully with minimal increases in the fiscal and manpower resources currently available. Options for additional resources should be considered first at the state level, potentially with the involvement of the state attorney general.

The development of a single, simple protocol would be helpful. In some areas, implementing such a protocol would probably be a great improvement compared to the various sets of procedures that exist (or do not exist) in those communities today.

Incentives

Federal grants to promote the use of the protocol would be of help. Computer hardware and software could be supplied. Money, manpower, and educational credits should be provided for trainers and trainees. Incentives must be positive; negative approaches will generate only irritation or anger. As part of the whole, provision of training and feedback can also serve as incentives.

Piloting

A pilot model of the standardized protocol should be tested first in jurisdictions that are already using their own death scene investigation protocols as those centers clearly possess the resources, and in other areas that have no such experience and/or resources, that is, "fertile" and "non-fertile" areas. Emphasis on the positive aspects of this "pilot experience" should be used at the outset to enlist local support.

Endorsements

Endorsements should be sought from any and all agencies with potential interest in the use of standardized death scene investigation. Support for the concept of any standardized protocol should probably be obtained first before it is sought for a specific standardized protocol.

Mandate

A mandate for a specific protocol could be made through professional associations rather than by law. A federal mandate would be an option but may be difficult to enforce in states. A federal mandate could require that states meet a minimum standard but it could not require the use of a specific protocol. The protocol could be integrated within professional practice guidelines, and should be part of a local community standard of practice.

Any legal mandate must be established at the state and/or local level but federal support might provide some incentive. However, participant opinions were mixed about whether or not a legal mandate should be established. Ultimately, scene investigation should be considered part of "public health" practice and not law.

Core Data Items

More than 70 core data items were identified, and in addition to basic socio-demographic and medical history data for the mother and infant, includes information to be obtained from or about the biological mother, the primary caretaker, the caregiver at the time of the incident, the biological father, the person who discovered the unresponsive infant, first responders, other witnesses, and health care providers. Information and observations about the general home characteristics, sleeping environment and position, and bedding materials were also included as core items. The specific core items will appear in the guidelines currently planned for publication in 1994.

Conclusions

The "Workshop on Guidelines for Scene Investigation of Sudden Unexplained Infant Deaths was successful in generating a variety of ideas concerning the desirable attributes of a standardized protocol for the scene investigation of sudden, unexplained infant deaths, including items of information essential to such a protocol such as certain training needs, specification of procedures for data collection, data reporting, quality assurance, and strategies for implementation. This information can now be considered by the HHS Interagency SIDS Panel to develop specific guidelines for developing a standard scene investigation protocol. Guidelines, including specific core data items, are expected to be published in the CDC's MMWR in the Fall of 1994.

References

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[2] Willinger, M., James, L. S., and Catz, C., "Defining the Sudden Infant Death Syndrome (SIDS): Deliberations of an Expert Panel Covened by the National Institute of Child Health and Human Development," *Pediatric Pathology*, Vol. 11, 1991 pp. 677–684.

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