J Forensic Sci, Oct. 1976, Vol. 21, No. 4

SPECIAL REPORT

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The Examination of the Sudden Infant Death Syndrome Infant: Investigative and Autopsy Protocols

In 1975, the Office of Maternal and Child Health of the U.S. Department of Health, Education and Welfare awarded grants to 24 communities for the management of Sudden Infant Death Syndrome (SIDS) information and counseling projects. Four basic project guidelines were advocated: (1) the performance of autopsies on all infants dying suddenly and unexpectedly, (2) prompt notification of the parents of the results of the autopsy, (3) use of "SIDS" on the death certificate rather than other designations of the cause of death, (4) follow-up information and counseling for SIDS families provided by a health professional knowledgeable of the nuances of SIDS.

Since most of the grants were awarded to communities in which appropriate pathological examinations were already being conducted, the grant funds were for management, educational, and counseling services. A small portion of the funds was allocated to augment autopsy examinations in those communities unable to support the examinations or to extend the service to adjoining geographic areas.

Early in the evolution of the projects, it became apparent that a need existed for the standardization of investigative and autopsy procedures to assure uniformity of reporting in order to effectively analyze and compare the results of the programs. A special grant was awarded to the Office of the Medical Investigator, School of Medicine, University of New Mexico, to conduct a conference of project pathologists to develop minimal investigative and autopsy examination protocols. The conference was held 20–21 Nov. 1975, in Santa Fe, N.Mex. with Dr. Bruce Beckwith, of the University of Washington in Seattle, a well-recognized SIDS authority, as conference chairman and director of the investigation committee. Dr. Marie Valdes-Dapena of St. Christopher's Hospital and Temple University, widely acknowledged for SIDS research, directed the autopsy investigation committee. Dr. Richard Froede, then of the Armed Forces Institute of Pathology, recognized for quality control expertise, directed the quality control committee, and Dr. George Gantner from St. Louis University, an expert in data systems and registries, was the director of the registry committee.

The SIDS project directors were asked to nominate the project pathologists for the conference and most were able to attend. In addition, representatives of the National

Presented at the 28th Annual Meeting of the American Academy of Forensic Sciences, Washington, D.C., 20 Feb. 1976. The conference was supported under SIDS Information and Counseling Grant MCH-000022.

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Association of Medical Examiners and the Pathology and Biology Section of the American Academy of Forensic Sciences were invited with the expectation that they would report the conclusions and recommendations of the conference to their organizations. Information on gathering toxicological data was provided by two special guests, Bryan Finkle, of the University of Utah, and Dr. Robert Forney, Jr., of the University Hospitals of Cleveland. A complete list of conference participants is provided in Table 1.

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Investigation Committee Conclusions

The investigation committee agreed that if an initial scene investigation is conducted by a law enforcement agency or medical examiner, a copy of that report should be included with the investigation protocol. The follow-up detailed inquiry into the circumstances of death should be conducted by an individual thoroughly acquainted with all the nuances of SIDS, preferably not identified with a punitive agency, and definitely not in a punitive manner. It was further agreed that a more meaningful inquiry would result if the interview was conducted at an appropriate interval after death, a minimum of two weeks but preferably one month.

A computer-adaptable investigation protocol was developed, comprised of the minimum data to be obtained on each case with emphasis on the gathering of subject (SIDS infant), parental, gestational, familial, socioeconomic, and environmental data (Tables 2–5). The protocol was designed to acquire the minimum investigative data so that all programs could utilize the protocol under current funding limitations. It was recognized that a few programs are much more vigorous in the amount of investigative data they collect. They were not discouraged from continuing, but were asked to insure completion of the minimal protocol established by the committee.

TABLE 2—*Investigative findings before autopsy.*

The minimum investigative data to be obtained in each case should include these items.

ID#

Subject Data

Age (wks): _____ Date of Birth: _____

Sex: M _____ F _____

Race: _____

Last seen alive: Date: _____ Time: _____

Found dead: Date: _____ Time: _____

Observed to die: No: _____ Yes: _____ Describe: _____

Place of Death: Own Crib: _____ # in bed: _____

Parents' bed: _____

Other: _____ Describe: _____

Resuscitation attempted: Yes: _____ No: _____ Unknown: _____

Birth weight: _____

Illness in last two weeks: Yes: _____ No: _____

Cold, sniffles: _____

G.I. symptoms: _____

Other minor: _____

Other major: _____ Describe: _____

Medical treatment during last week of life: Yes: ____ No: ____ Unknown: ____

Prior major illness: Yes: _____ No: _____ Unknown: _____

Well baby visits: Yes: _____ No: _____ Unknown: _____

Breast fed: Yes: _____ No: _____ Unknown: _____

At time of death: Yes: _____ No: _____ Unknown: _____

Any cow's milk in past: Yes: _____ No: _____ Unknown: _____

TABLE 3—*Parental and gestational data.*

Maternal age (yrs): _____ Married: _____ Single: _____

Widowed: _____ Divorced: _____

Paternal age (yrs): _____

Length of gestation (wks): _____ (40 wks = term)

Complications of gestation: Yes: _____ No: _____ Describe: _____

Complications of delivery: Yes: _____ No: _____ Describe: _____

Number of prenatal visits: 0 _____ 4 _____

1 _____ Greater than 4 _____

2 _____ Unknown _____

3 _____

Unusual nutritional habits: _____

Unusual drug usage: _____

TABLE 4—*Familial data.*

Other SIDS cases: Yes: _____ No: _____ Describe: _____

Number of previous pregnancies: _____

Number of live births: _____

Number of living sibs: _____

Comments: _____

TABLE 5—*Socioeconomic and environmental data.*

Family income:	less than $5,000/yr _____ Welfare: Yes: _____ No: _____
	$5-10,000/yr _____
	$10-20,000/yr _____
	more than $20,000/yr _____
Address where death occurred:	_____
Home characteristics:	Single family: _____ Multifamily: _____
General quality of dwelling:	Below Average: _____
	Average: _____
	Above average: _____
Number of inhabitants in family dwelling:	Adults: _____
	Children: _____
	Smokers: _____
Unusual environmental circumstances:	Yes: _____ No: _____ Describe: ____
Neighborhood:	Urban industrial _____
	Urban (dense) residential _____
	Suburban (non-dense) residential _____
	Semi-rural (less than 1 home/acre) _____
	Rural (less than 1 home/10 acres) _____

Autopsy Committee Conclusions

The autopsy committee agreed that an initial letter of invitation to each potential participating pathologist should include the following items:

(1) a list of differential diagnoses comprising the most important causes for sudden, unexpected, explicable deaths to be ruled out in the course of the autopsy (Table 6);

(2) a list of the gross and microscopic observations to be expected in the performance of an SIDS autopsy (Table 7);

(3) a checklist of important observations to be noted in suspected SIDS deaths (Table 8);

(4) a list of organs on which microscopic examination should be conducted (Table 9); and

(5) a list of ancillary procedures which could enhance the report and may be included with any case if judged indicated and feasible by the reporting pathologist (Table 10).

The committee concluded that for the purposes of the program, a standard autopsy protocol should not be dictated by any committee. Instead, each participating pathologist would be asked to prepare and submit (1) a copy of his standard autopsy protocol prepared in his customary fashion, including observations on at least the tissues designated in Table 9; (2) a completed autopsy checklist (Table 8); and (3) results of any ancillary procedures conducted.

The list of requested microscopic sections (Table 9) was agreed to be the *minimum* microscopic examinations required to adequately examine an SIDS infant. Pathologists were not discouraged from examining more tissues than those listed, but were requested to conduct the listed examinations uniformly.

The committee unanimously agreed that SIDS autopsies should be performed by or under the direct supervision of board-certified pathologists, and, if at all possible, on unembalmed infants.

Quality Control Committee Conclusions

The quality control committee agreed that the mission of quality control would be

TABLE 6—*List of major differential diagnoses in the sudden, unexpected death of a previously well infant, exclusive of crib death.*

General:	Sepsis (including meningococcemia)
Blood:	Sickle cell anemia with thrombosis
Heart:	Congenital heart disease (including aortic stenosis)
	Myocarditis (especially Coxsackie)
	Subendocardial fibroelastosis (endocardial sclerosis)
Lungs and Airways:	Pneumonia
	Bronchiolitis
	Pulmonary arteriolar sclerosis (pulmonary hypertension)
	Tracheobronchitis
Kidney:	Poisoning
	Pyelonephritis
G.E. Tract:	Enterocolitis (with diarrhea and dehydration), *Salmonella, Shigella,* and occasional pathogenic *E. Coli*
Liver:	Hepatitis (including Coxsackie)
	Poisoning
Pancreas:	Pancreatitis (including Coxsackie)
	Cystic fibrosis of the pancreas (sudden death in hot weather)
	Boric acid poisoning
Adrenal:	Congenital adrenal hyperplasia
Brain:	Meningitis
	Encephalitis
	Trauma (fractures, edema, subdural hemorrhage)
	Arteriovenous malformation
Skeleton:	The battered child (see brain above)

TABLE 7—*Morphologic observations typical of crib death.*

	External Examination
Body:	moderately well developed and well nourished
External nares:	frothy and even blood-tinged mucus may be present
	Internal Examination
Pleural surfaces:	many petechiae apt to be present
Thymus:	many petechiae apt to be present
Heart:	many petechiae apt to be present in the epicardium; contains blood, usually in liquid state
Lungs:	tend to fill the pleural cavities completely; often exhibit moderate edema and congestion
Lymphoid structures:	almost too well preserved (example, mesenteric lymph nodes)
Adrenals:	tend to be small within limits of normal
	Microscopic Observations
General:	those features which correspond to the above
Larynx and Trachea:	moderate degree of "subacute" inflammation involving the mucosa (in about 50% of cases)

to provide a coordinated program of securing valid data from the SIDS projects. This mission would be accomplished by the following procedures:

1. The SIDS investigative protocols and autopsy data would be standardized.

2. The standardization or equivalency of terminology, including a glossary of terms, definitions of the terms, and a suitable coding scheme where appropriate, would be accomplished.

3. Administrative or professional control would be exercised over the source data by internal and external auditing for reproducibility and conformity of conclusions. A

TABLE 8—*Autopsy checklist to accompany protocol.*

External Examination

Body length (crown to heel) _____ cm
Body weight _____ g
State of development: Good: _____ Poor: _____
State of nutrition: Good: _____ Poor: _____
Nares exhibit: Foam: ____ Bloody foam: ____ Mucus: ____ Other: _____
Dehydration: Present: _____ Absent: _____
Rash: Present: _____ Absent: _____
Anomalies:_____ None:_____
Evidence of injury: _____
_____
_____
Nares and choanae: Probe patent: _____ Not probe patent: _____

Internal examination

Petechiae: Thymus: Present: _____ Absent: _____
Pleura: Present: _____ Absent: _____
Epicardium: Present: _____ Absent: _____
Heart: Character of any contained clot: _____ No clot present: _____
Epiglottis: Examined: Yes: _____ No: _____
Color of mucosa: _____ Content of lumen: _____
Larynx: Examined: Yes: _____ No: _____
Color of mucosa: _____ Content of lumen: _____
Trachea: Examined: Yes: _____ No: _____
Color of mucosa: _____ Content of lumen: _____

TABLE 9—*List of requested microscopic sections (or equivalent blocks or wet tissue).*

1. Heart (1 vertical section including left atrium and ventricle)	1
2. Lungs (1 section of each lobe—5 in all)	5
3. Kidney	1
4. Ileum (including a Peyer's patch)	1
5. Liver	1
6. Pancreas	1
7. Adrenal	1
8. Trachea	1
9. Thymus	1
10. Brain (mid-pons and base of brain in the vicinity of the Circle of Willis—each to include meninges)	2
Total	15

registry could serve as a quality control resource for the auditing checks. Internal auditing might include prosector coding, comparative data checking, and double checking by double abstracting. External checks might include coding of sample protocols by multiple centers and submitting data to other groups for interpretation and comparison. Supplementary checks by an auditing team could also be utilized, although this would be rather expensive.

4. Proficiency testing programs should be considered to evaluate gross and microscopic pathological observations and case interpretation.

5. Control groups should be studied by matching into pairs sudden, unexpected traumatic infant deaths.

TABLE 10—*Ancillary procedures (whenever indicated and feasible).*

1. Total body X-rays for evidence of repetitive battering and so forth
2. Biochemical determinations using vitreous humor
3. Microbiology
   a. Bacterial cultures of
      (1) Heart blood
      (2) Spleen
      (3) Each lung
      (4) Swab of the larynx
      (5) Stool
      (6) Cerebrospinal fluid
   b. Viral cultures of
      (1) Heart
      (2) Lungs
      (3) Kidney
      (4) G.I. tract
      (5) Brain
4. Toxicology
   Collection of: Blood (5 to 10 ml of whole blood)
   Liver (approximately 10 g)
   Spinal fluid (any amount available)
   Urine (any amount available)
   Gastric contents (any amount available)
   For determination of the presence and levels of
   a. Common agents acting upon the central nervous system
   b. Alcohols
   c. Salicylates (to be tested for in the most sensitive way)
   d. Carbon monoxide
   e. Other agents as appropriate to the case

Registry Committee Conclusions

As most program jurisdictions do not have sufficient cases to provide an ideal statistical base, it was agreed that cooperative efforts would be highly desirable in establishing a large data base. These would ensure the most efficient use of project funds in that the data base would allow conclusions on a large national sample. The registry would constitute a technique for full utilization of the potentials of uniform protocols, thus avoiding data deficiencies which might make later analysis difficult or impossible. A centralized computer facility as part of the registry could analyze the pooled data most efficiently by providing a mechanism for comparison of individual program data with that in the pool. This would quickly identify variations in experience from one center to another and allow programs to respond quickly to new approaches. The centralized data storage would provide extensive support for quality control functions. Special search questions could be posed to this data base. Periodically, statistically analyzed subsets and the whole data base could be dispatched to each center, allowing comparison of individual program data with the pool.

Considerations for funding the registry should include development costs, maintenance, types of reports generated, types of forms necessary, and the maintenance of the data base after project termination. The registry might also act as a clearinghouse for specimens, slides, and fluids, which, after acquisition, could be reviewed by a quality control group.

Special considerations of registry establishment should also include ownership of, access to, and publications generated from pooled information; the privacy act; and freedom of information laws.

Post-Conference Questionnaire Results

Following the conference all project pathologists were afforded an opportunity to express individual viewpoints in seven major areas of concern including legislation, investigation, examination, certification, counseling, quality control, and registry establishment. This was accomplished by individual, mailed questionnaires, returned by most of the committee.

The majority advocated a local coroner or medical examiner law which required reporting of all sudden and unexpected deaths of infants but afforded discretion in the decision of autopsy in these deaths. It was agreed that local legislative bodies should be advised of the desirability of examination of all such deaths and the necessity to provide appropriate resources. Virtually all agreed that family counseling should be voluntary. On-scene investigation was urged by most respondents, preferably by a well-trained representative of the medical examiner or coroner. They also urged follow-up home investigation within 24 h if the infant had been moved to a hospital. Most indicated that the minimal investigative information contained in Tables 2–5 could be obtained with present resources.

All concurred with the examination requirements outlined in Tables 8–10, and most indicated that this could be accomplished with present resources. The majority of pathologists recognize the concept of an "administrative SIDS death" and, upon completion of the gross autopsy, when no competent cause of death is delineated, the cause of death is immediately certified as SIDS. Only a few certify the death certificate as "pending" until ancillary studies are completed.

In counseling families, most counselors indicate to the family that the most probable cause of death of their infant is SIDS when no competent cause of death is delineated without reference to further ancillary studies. Unless examinations reveal a pathological process which is of public health or family planning importance, the initial SIDS counseling afforded to the family remains unchanged. Trained public health nurses conduct the follow-up counseling in the family's home in most project communities.

The respondents virtually all agreed that quality control is considered desirable as soon as resources are available. Initially this should include review of the investigative and examination findings in all sudden, unexpected infant deaths, including those not reported as SIDS.

The establishment of a registry is uniformly agreed to be desirable, if not absolutely necessary, as soon as resources are available.

Summary

The results of a national conference of pathologists and other SIDS investigators are reported. The protocol guidelines developed at the conference are inclusive, yet remarkably concise and straightforward. These agreed-upon protocols should be utilized by pathologists working with SIDS information and counseling projects funded by the U.S. Department of Health, Education and Welfare. They may prove to be of value to medical examiners and other pathologists who perform investigations and autopsies on suspected SIDS infants. Quality control and the possibility of a registry are discussed.

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