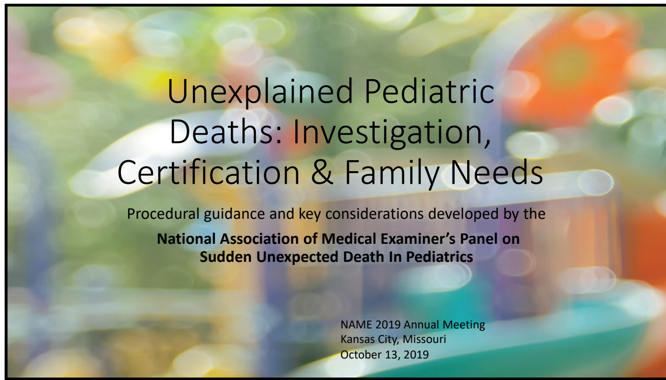
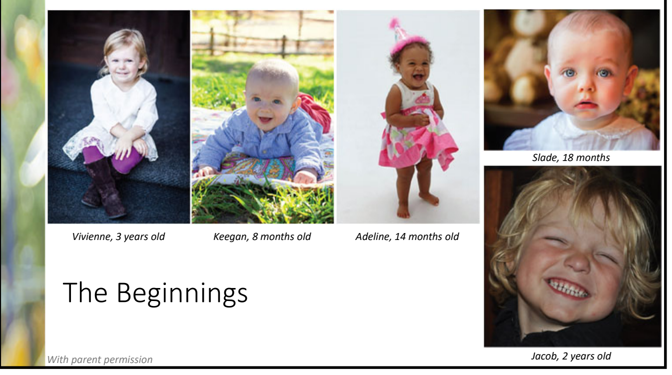


Disclosures

- NAME panel work funded by SUDC Foundation.
- Reference to book published by AFP.
- Employed by or receiving funding from:
  - NIH (M. Sens, R.Goldstein)
  - SUDC Foundation (L. Crandall)
  - Montgomery County Forensic Services (K. Pinneri)
  - Washoe County Regional Medical Examiner's Office (L. Knight)
  - University of North Dakota (M. Sens)
  - Vermont Office of the Chief Medical Examiner (E. Bundock)
  - National Association of Medical Examiners (M. Sens)
  - Boston Children's Hospital (R. Goldstein),
- Private Consultation Services
  - Knight Forensics, PLLC (L. Knight)
  - Gray Matter Forensic Consulting, LLC (E. Bundock)

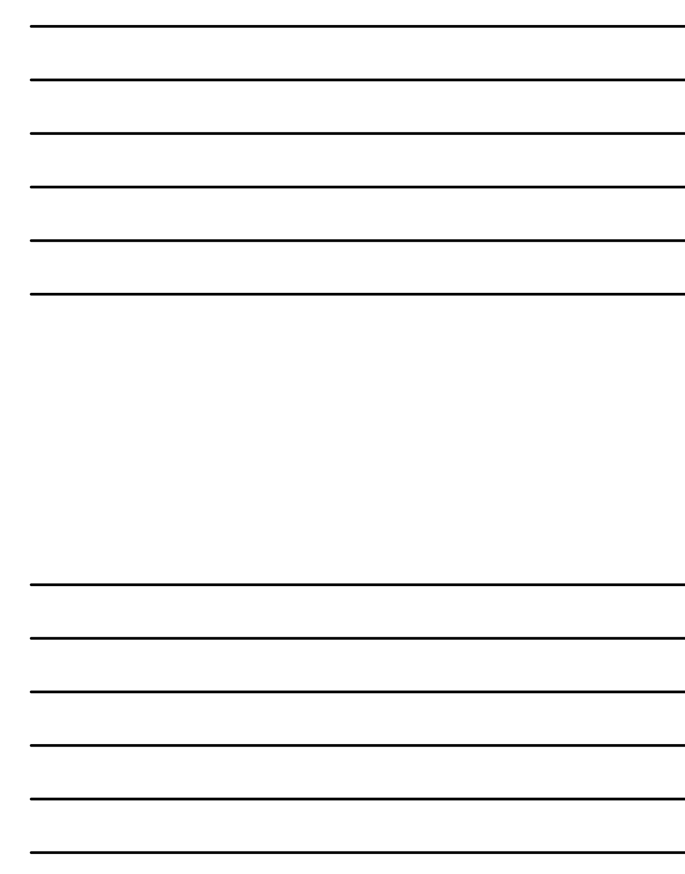


Background

- Challenge of infant deaths – NAME audience discussion 2013/2014
- 2016: AAP and NAME - revision of Child Abuse and SIDS paper
- Funding modeled after Opiate Grant / SUDC Funded
  - Committee of NAME / AAP; library support; advisory members (Feds, researchers, SUDC)
  - Two face-to face meetings; teleconferences
- Manuscript / position paper NAME / AAP

Response (single NAME post; one week)

- 32+ NAME members
  - More as project evolved
- 6 AAP members (+ others)
- Volunteer librarian – NYU
- SUDC, NYU, other researchers
- NIH (3 institutes), CDC
- Initial: One committee of 17
- Plan B: "Main" committee with members chairing subcommittees; subcommittee members not at in-person meetings
- Final:
  - Everyone on "main committee" and invited to face to face meetings
  - Multiple subcommittees based on initial question plan and evolving needs



Responding:

NAME Fellows / Members

- Tom Andrews
- Roger Byard
- Elizabeth Bundock
- Rudi Castellani
- Tracey Corey
- Giancarlo DiVella
- Eric Eason
- Wendy Gunther
- Heather Jarrell
- Laura Knight
- Kristin Landi
- Kelly Lear-Kaul
- Adele Lewis
- Evan Matshes
- Anna McDonald
- Othon Meda
- Nathaniel Patterson
- Kathryn Pinneri
- Donald Pojman
- Reade Quinton
- Valerie Rao
- Lakshmanan Sathyavagiswaran
- Mary Ann Sens
- Christina Stanley
- Jane Willman Turner
- Steven M White

Investigator / Coroner

- Stacey Drake
- Jennifer Winner
- Karla Orozco
- Dotti Owen
- Rose Psara
- Beoncia Loveless

Fellow

- Brandi McCleskey

National

- NIH: Ruth Brenner, Valerie Maholmes, Kristin Burns, Marion Koso-Thomas
- CDC: Margaret Warner, Carrie Shapiro-Mendoza, others
- NCHS / US WHO: Robert Anderson

Experts, AAP, SUDC

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- Isabel Barata
- Susan Berry
- Erin Bowen
- Derek Bruce
- Frank Cecchin
- Ruey-Kang Chang
- Laura Crandall
- Orrin Devinsky,
- Arline Faustin
- Amanda Kay
- Declan McGuone
- Rachael Moon
- Vince Palusci
- James Robinson
- Nori Williams

Librarians

- Aileen McCrillis
- Cynthia Schmidt

National Association of Medical Examiner's
Panel on Sudden Unexpected Death In Pediatrics

- Tracey Corey, Co-Chair and Editor
- Elizabeth A. Bundock, Co-Chair and Editor
- Michael J. Ackerman
- Thomas A. Andrew
- Isabel Barak
- Derek Bruce
- Susan Berry
- Erin Bowen
- Kristin Burns
- Rudolph Castellani
- Laura Gould Crandall
- Orrin Devinsky
- Stacy A. Drake
- Eric Eason
- Wendy Gunther
- Amanda J. Kay
- Laura Knight
- Kristen Landi
- Kelly Lear
- Adele Lewis
- Evan Matshes
- Brandi McCleskey
- Rachel Y. Moon
- Vincent J. Palusci
- Kathryn Pinneri
- Cynthia Schmidt
- Mary Ann Sens
- Carrie Shapiro-Mendoza
- Jane W. Turner
- Margaret Warner
- Steven White
- Nori Williams

Workshop Presenters

Preliminary Framing Questions and Initial Committees

- All pediatric sudden deaths
- Potential mechanisms, evidence available, evidence needed
  - Neuropath / Neurologic
  - Infectious
  - Cardiac
  - Genetic
  - Metabolic / other natural
  - Asphyxia / other un-natural
- Basic and optimal death investigation needed, variations for age
- Risk factors, prevention
- Autopsy performance and ancillary testing
- Communication needed: Family, professionals, health systems, public health
- Certification (what information, where should it go, alternative models, manner, risk factors, etc.)
- Reporting, tracking, evaluation
- Research needs and direction

Results

- Large, fluid committee and subcommittees
- Over three years of work – started in late 2016
  - Massive reference collection, organization and review
  - 19 main committee conference calls (1 – 4+ hours in length); other subcommittee activities; spirited and passionate discussion
  - Two in-person 2 day meetings; one lunch in person meeting at NAME; editors retreat
- Support by SUDC:
  - Anticipated publication of book, Nov, 2019
- Heroic efforts of Tracey Corey and Elizabeth Bundock
- Collaboration with Radcliffe project – shaped discussions

Procedural Guidance/Key Considerations for
Scene investigation
Autopsy and ancillary testing
Certification and Surveillance
Synoptic Reporting
Family and professional interactions

Unexplained Pediatric Deaths
Investigation, Certification, and Family Needs
Elizabeth Bundock & Tracey Corey, Editors

The 3rd International Congress on Sudden Death in Infants and Children,

Radcliffe Institute for Advanced Study, Harvard University November 26-27, 2018

Inconsistent Classification of Unexplained Sudden Deaths in Infants and Children Hinders Surveillance, Prevention and Research. FSMP, Online 9/9/19

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Workshop Presenter

Medicolegal Death Investigation

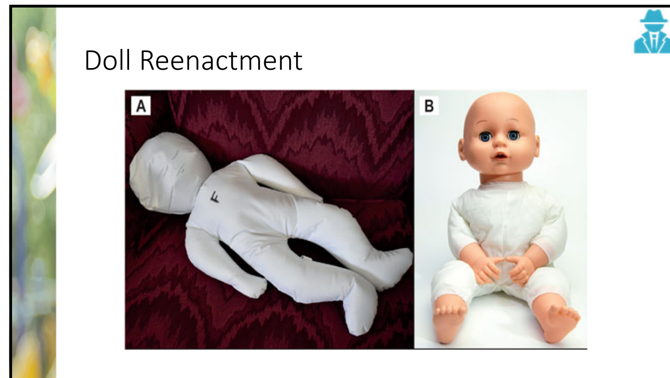
- Children are not small adults
  - Infants, toddlers, school aged children, pre-teens, tweens, teenagers
  - All have different concerns, developmental abilities and milestones
- Any child death falling under the jurisdiction of a medical examiner/coroner should be investigated by a certified medicolegal death investigator, independent from law enforcement
- Information obtained relies on parents, caregivers and other relatives
  - Often distraught at the scene/hospital
  - May or may not have played a role in the death
  - Delicate balance: obtaining information needed for investigation while being sensitive to the family's grief

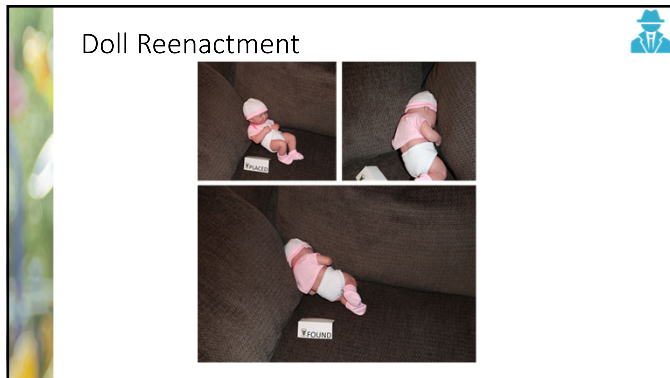
Medicolegal Death Investigation

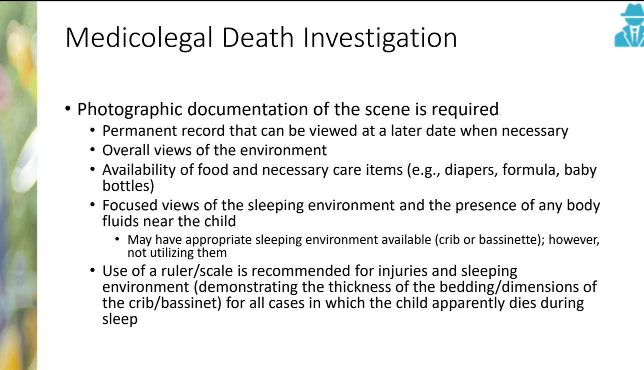
- Scene investigation is critical
  - Should be performed within 24 hours even when the child has been transported to the hospital, to include evaluation of any potential hazards or exposures
  - Individual death scene investigation requirements will vary based on the circumstances surrounding the death and the age and developmental capabilities of the child
  - The child's environment plays a much larger role in death investigation than most adults
- In cases of death during apparent sleep, the sleeping environment should be documented to include softness, such as the presence of a pillow top mattress and excessive bedding materials

Medicolegal Death Investigation

- Must visit and photograph the environment where the child was initially found
- Doll reenactment is recommended for deaths during apparent sleep of all children up to 24 months of age, developmentally delayed children, and children with a seizure history to document the position of the child when placed to sleep and when found
- Best to use a doll brought with you; avoid using something in the residence if possible
  - Store bought baby doll
  - Weighted featureless doll (purchased online)
- Use placards denoting "found" and "placed"

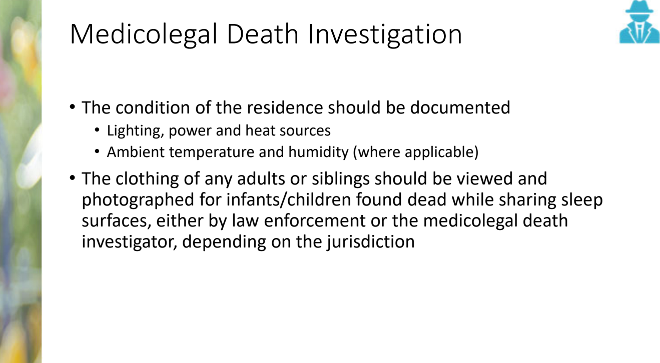

Doll Reenactment
A
B


Doll Reenactment

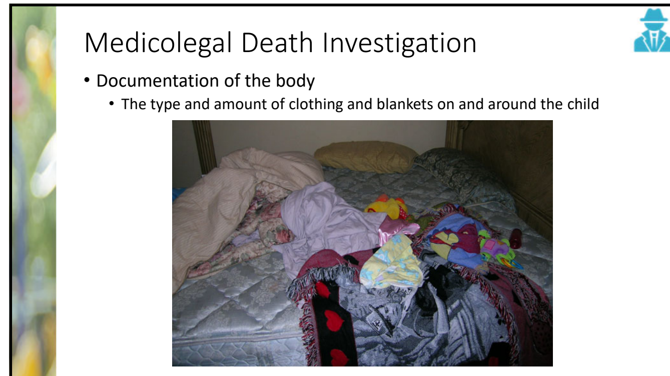

Medicolegal Death Investigation
• Photographic documentation of the scene is required
• Permanent record that can be viewed at a later date when necessary
• Overall views of the environment
• Availability of food and necessary care items (e.g., diapers, formula, baby bottles)
• Focused views of the sleeping environment and the presence of any body fluids near the child
• May have appropriate sleeping environment available (crib or bassinette); however, not utilizing them
• Use of a ruler/scale is recommended for injuries and sleeping environment (demonstrating the thickness of the bedding/dimensions of the crib/bassinet) for all cases in which the child apparently dies during sleep

Medicolegal Death Investigation
GRACO

Medicolegal Death Investigation
Robitussin

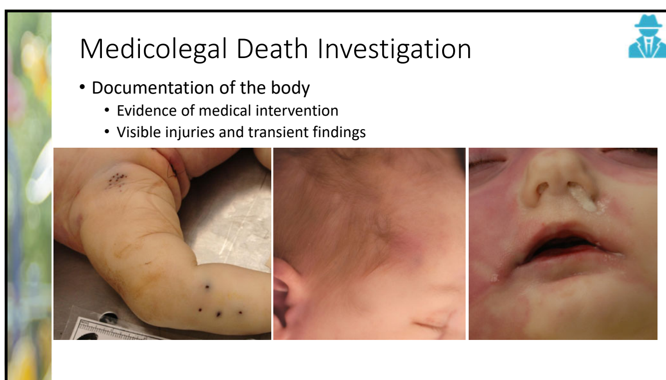

Medicolegal Death Investigation
• The condition of the residence should be documented
• Lighting, power and heat sources
• Ambient temperature and humidity (where applicable)
• The clothing of any adults or siblings should be viewed and photographed for infants/children found dead while sharing sleep surfaces, either by law enforcement or the medicolegal death investigator, depending on the jurisdiction

Medicolegal Death Investigation

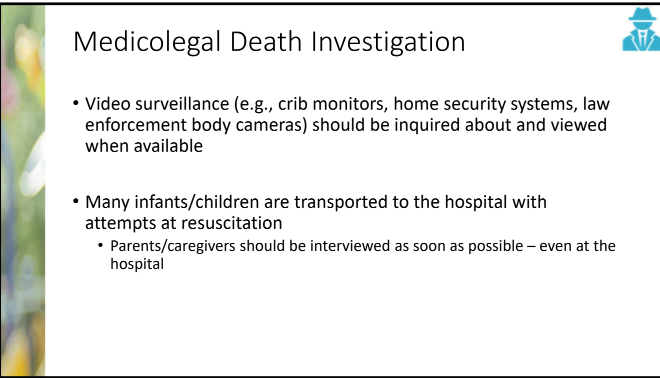

Medicolegal Death Investigation
• Documentation of the body
• The type and amount of clothing and blankets on and around the child

Medicolegal Death Investigation
• Documentation of the body
• The type and amount of clothing and blankets on and around the child
• Other objects near child

Medicolegal Death Investigation
• Documentation of the body
• The presence and pattern of lividity
• The presence of rigor mortis



Medicolegal Death Investigation
• Documentation of the body
• Evidence of medical intervention
• Visible injuries and transient findings



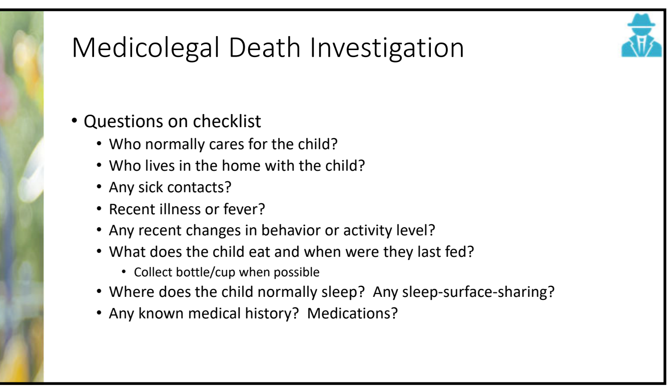
Medicolegal Death Investigation
• Video surveillance (e.g., crib monitors, home security systems, law enforcement body cameras) should be inquired about and viewed when available
• Many infants/children are transported to the hospital with attempts at resuscitation
• Parents/caregivers should be interviewed as soon as possible – even at the hospital

Medicolegal Death Investigation

- Use of an infant/child death reporting form is recommended
  - Ensures required information is gathered uniformly, including housing and living environment, developmental milestones passed, caregiver arrangements, and school information (when applicable)
  - As a standard practice, may help the family feel less interrogated
  - Provides background information for obtaining necessary records
- Best practice: ask all the questions, all the time, as soon as possible

Medicolegal Death Investigation

- Sudden unexplained infant and child death reporting forms
  - Checklist with all information needed for pediatric death investigation
  - Infant form recently revised by CDC
  - Childhood form developed by Panel



Medicolegal Death Investigation

- Questions on checklist
  - Who normally cares for the child?
  - Who lives in the home with the child?
  - Any sick contacts?
  - Recent illness or fever?
  - Any recent changes in behavior or activity level?
  - What does the child eat and when were they last fed?
    - Collect bottle/cup when possible
  - Where does the child normally sleep? Any sleep-surface-sharing?
  - Any known medical history? Medications?

Medicolegal Death Investigation

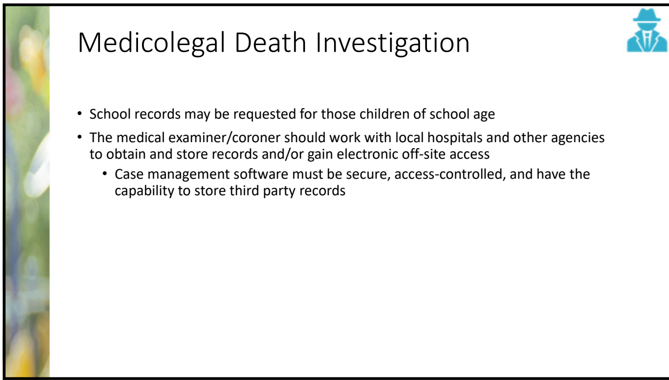
- Seizure history
  - Age at onset, etiology
  - Known triggers, Febrile
  - Frequency and type (s); Last seizure
  - Medication/dosage, recent medication changes
  - Family history of seizures
- Developmental milestones are important!!
  - Vary with age
  - Rolling over, crawling, cruising, walking, etc
  - Delayed children will have altered milestones – get as specific information as possible

NAME POSITION PAPER AFP

National Association of Medical Examiners Position Paper: Recommendations for the Investigation and Certification of Deaths in People with Epilepsy

Medicolegal Death Investigation

- Information/records needed for sudden unexplained pediatric deaths
  - Mother's obstetrician
  - Birth hospital
    - Gives starting point for weight and length
    - Provides type of delivery and any complications
  - Pediatrician
    - Request all visits, including growth charts, newborn screening results and immunizations
  - Terminal hospital/ER records
  - Prior ER/hospital records
  - EMS records
    - May need documentation of type of CPR performed
    - Provides great initial information (scene environment, body position, cardiac rhythm, capillary blood glucose



Medicolegal Death Investigation

- Cell phone and social media photographs and videos of the child prior to death may be obtained from the parents/caregivers.
- The death investigator should be familiar with current social media platforms and work with parents/law enforcement agencies to gain access to electronic devices when necessary.

Medicolegal Death Investigation

- Removal of the child from the residence should be performed with care and compassion
  - Recommended that the child be wrapped in a sheet or blanket and carried to the transport vehicle, to be placed inside a body bag and/or transport box
- Some states/jurisdictions have laws allowing viewing of a deceased child
  - Usually requires supervision
  - Be as accommodating as possible without jeopardizing the investigation

Autopsy and Ancillary Testing

Workshop Presenter: Laura Knight, MD.

Autopsy and Ancillary Testing

- What is a complete autopsy?
- What is a complete pediatric autopsy?
- To what extent must we preserve biospecimens for future analysis with advances in testing?
- Research?
- Resources?
  - Equipment and supplies
  - Storage capacity, freezers
  - Funding
  - Personnel/staffing

Autopsy and Ancillary Testing

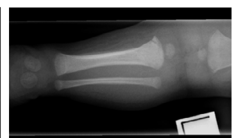
Procedural Guidance

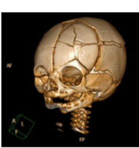
- **An autopsy must be performed in all sudden unexpected deaths in infants and children**
  - unless prohibited by law (such as in cases of religious objection in certain states).
- **The autopsy should be performed promptly** and as soon as practical following death, to preserve the quality of diagnostic specimens
  - including those for microbiological, genetic, and metabolic studies.

Autopsy and Ancillary Testing

Procedural Guidance

- **A radiologic skeletal survey should be performed** in all infants and young children.
  - Consultation with a pediatric radiologist, if available, may be considered.
  - Memoranda of understanding may be established with local hospitals to obtain postmortem skeletal surveys in cases in which the infant or child is transported to the hospital.





Autopsy and Ancillary Testing

Procedural Guidance

- **Histology and comprehensive toxicology must be performed** in all sudden unexpected deaths in infants and children.
- In deaths that remain unexplained after gross autopsy examination, additional testing should be performed:
  - **Microbiological cultures** (and other related studies), directed by the case history and autopsy findings.
  - **Molecular testing** may be performed in conjunction with cultures, and specimens should be preserved for additional **infectious disease-related** molecular testing methods if indicated later.
  - **Chemical analysis of vitreous fluid** for electrolytes and glucose should be performed.

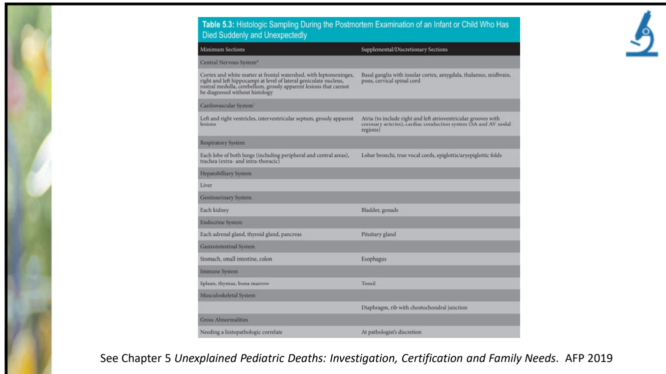


Table 5.3: Histologic Sampling During the Postmortem Examination of an Infant or Child Who Has Died Suddenly and Unexpectedly

Minimum Sections	Supplemental/Discretionary Sections
Central Nervous System*	
Cortex and white matter at frontal watershed, with leptomeninges, right and left hippocampi at level of lateral geniculate nucleus, rostral medulla, cerebellum, grossly apparent lesions that cannot be diagnosed without histology	Basal ganglia with insular cortex, amygdala, thalamus, midbrain, pons, cervical spinal cord
Cardiovascular System†	
Left and right ventricles, interventricular septum, grossly apparent lesions	Atria (to include right and left atrioventricular grooves with coronary arteries), cardiac conduction system (SA and AV nodal regions)
Respiratory System	
Each lobe of both lungs (including peripheral and central areas), trachea (extra- and intra-thoracic)	Lobar bronchi, true vocal cords, epiglottis/aryepiglottic folds
Hepatobilliary System	
Liver	
Genitourinary System	
Each kidney	Bladder, gonads
Endocrine System	
Each adrenal gland, thyroid gland, pancreas	Pituitary gland
Gastrointestinal System	
Stomach, small intestine, colon	Esophagus
Immune System	
Spleen, thymus, bone marrow	Tonsil
Musculoskeletal System	
	Diaphragm, rib with chostochondral junction
Gross Abnormalities	
Needing a histopathologic correlate	At pathologist's discretion

See Chapter 5 *Unexplained Pediatric Deaths: Investigation, Certification and Family Needs.* AFP 2019

Autopsy and Ancillary Testing

Procedural Guidance

Genetic testing

- **Preserve specimen to allow for later genetic testing**
  - a lavender top EDTA tube of blood at minimum
- **Ideally, screening tests for cardiac channelopathies and cardiomyopathies should be performed when all other testing is negative**, *prior* to finalizing cause of death as undetermined or equivalent.
- Other genetic studies (for metabolic and neurologic disorders, or directed genetic testing for specific cardiomyopathy) may be appropriate based on medical history, circumstances of death, and autopsy findings.
- It is understood that the yield of genetic testing is low in SUIDs, but somewhat higher in SUDC. It is critical to order in SUDC cases.
- DNA banking may be offered to families (at their cost) in "undetermined" cases with negative genetic screens.

Autopsy and Ancillary Testing
Procedural Guidance

Metabolic testing

- Must be performed whenever the clinical history or autopsy findings suggest a diagnosis of inborn error of metabolism;
  - clinical consultation may be useful in appropriately targeting the testing.
- **Routine** metabolic screening on all sudden unexplained infant and child deaths is **extremely low-yield**, and a negative result from a limited postmortem panel may provide false reassurance.
- At minimum, a metabolic blood/bile spot card should be prepared at the time of autopsy and held (to be later sent if indicated by unexpected findings).

Autopsy and Ancillary Testing

Procedural Guidance

Examining the brain

- The pediatric brain and spinal cord **should be preserved in formalin prior to sectioning,** photography, and histologic sampling if organ retention is not precluded by statute and the autopsy has not revealed a definitive cause of death. The intracranial dura may be examined with or without fixation.
- Examination by a neuropathologist experienced in forensic cases is recommended but at the discretion of the autopsy pathologist if resources are limited or retention of organs is restricted.; some offices do this as a matter of routine on SUID/SUDC cases

Autopsy and Ancillary Testing
Procedural Guidance

Examining the brain

Table 8.1: Histologic Sections for Neuropathologic Examination

Brain Region	Reason for Evaluation
* Cortex and white matter at frontal watershed, with leptomeninges	Assess cortical development; identify neuronal necrosis; screen for neuronal storage disorder; exclude meningitis and encephalitis
* Hippocampi, right and left, at level of lateral geniculate nucleus	Assess development; screen for sequelae or causes of seizure; identify neuronal necrosis
* Medulla, rostral	Contains centers for cardiorespiratory regulation and arousal
* Cerebellum	Involved in autonomic regulation; atrophy associated with epilepsy; identify neuronal necrosis
* Grossly apparent lesions that cannot be diagnosed without histology	Microscopic confirmation is needed for diagnosis
Basal ganglia with insular cortex	Insular cortex involved in autonomic regulation; screen for neuronal storage disorder and periventricular lesions associated with premature birth
Amygdala	Implicated in epilepsy and apnea; screen for gliosis and neuronal loss as sequelae of temporal lobe seizures
Thalamus	Screen for neuronal storage disorder and gliosis
Midbrain and Pons	Contains centers for cardiorespiratory regulation and cranial nerve nuclei
Cervical spinal cord	Necessary for cardiorespiratory regulation

* Recommended minimum sampling

See Chapter 8 *Unexplained Pediatric Deaths: Investigation, Certification and Family Needs.* AFP 2019

Autopsy and Ancillary Testing

Procedural Guidance

Examining the heart and great vessels

- The orientation of the heart and great vessels must be **examined *in situ*** in all pediatric cases. When abnormalities are already apparent, the heart, lungs, and thoracic aorta should be **removed *en bloc*** for further examination. Otherwise, the method of removal is **at the discretion** of the pathologist.
- In infants, the heart should be opened along lines of blood inflow and outflow.
- In older children, the adult method (transverse apical sections, followed by dissection of the heart base by blood inflow and outflow method) may be used.

Autopsy and Ancillary Testing

Procedural Guidance

Examining the heart and great vessels

See Chapter 7 *Unexplained Pediatric Deaths: Investigation, Certification and Family Needs.* AFP 2019

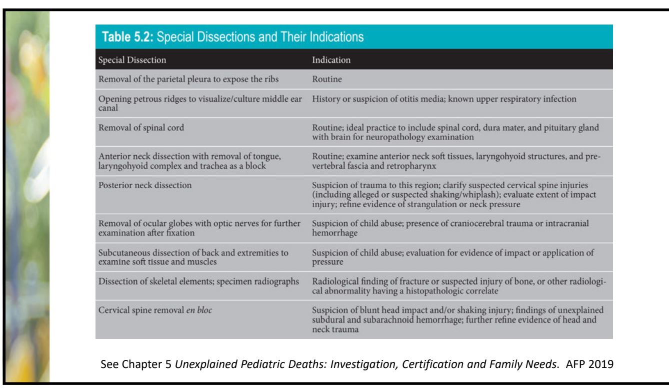


Table 5.2: Special Dissections and Their Indications

Special Dissection	Indication
Removal of the parietal pleura to expose the ribs	Routine
Opening petrous ridges to visualize/culture middle ear canal	History or suspicion of otitis media; known upper respiratory infection
Removal of spinal cord	Routine; ideal practice to include spinal cord, dura mater, and pituitary gland with brain for neuropathology examination
Anterior neck dissection with removal of tongue, laryngohyoid complex and trachea as a block	Routine; examine anterior neck soft tissues, laryngohyoid structures, and pre-vertebral fascia and retropharynx
Posterior neck dissection	Suspicion of trauma to this region; clarify suspected cervical spine injuries (including alleged or suspected shaking/whiplash); evaluate extent of impact injury; refine evidence of strangulation or neck pressure
Removal of ocular globes with optic nerves for further examination after fixation	Suspicion of child abuse; presence of craniocerebral trauma or intracranial hemorrhage
Subcutaneous dissection of back and extremities to examine soft tissue and muscles	Suspicion of child abuse; evaluation for evidence of impact or application of pressure
Dissection of skeletal elements; specimen radiographs	Radiological finding of fracture or suspected injury of bone, or other radiological abnormality having a histopathologic correlate
Cervical spine removal *en bloc*	Suspicion of blunt head impact and/or shaking injury; findings of unexplained subdural and subarachnoid hemorrhage; further refine evidence of head and neck trauma

See Chapter 5 *Unexplained Pediatric Deaths: Investigation, Certification and Family Needs.* AFP 2019

Autopsy and Ancillary Testing
Procedural Guidance

- **Communication should be considered a step in the autopsy.**
- Preliminary results to family, law enforcement, other stakeholders within 48 hours
  - anticipated scope of testing
  - turnaround times
  - who they should contact for updates or questions.
- Final results and the cause of death to the family
  - verbally (by scheduled appointment, either via telephone or in-person)
  - and in writing (ie, report if desired)
  - Include a cover letter warning family what is enclosed (ie, autopsy report)
  - A written request from the family for this information may be required in some states.
- Family should have the opportunity to ask questions of the pathologist in order to best understand the findings in the report.

Autopsy and Ancillary Testing

Procedural Guidance

- **The autopsy report should include a detailed opinion section that explains the rationale** for the cause and manner of death determination
  - written in a manner accessible to the lay reader,
  - questions about unusual results or circumstances should be anticipated and explained proactively
- The opinion section may include recommendation for clinical evaluation and genetic testing for surviving family members when a genetic condition remains in the differential diagnosis.
  - Or this recommendation may be made in a separate letter to the family
- Synoptic reporting and death certificate completion, up next

Autopsy and Ancillary Testing

- **Greater financial support MUST be provided to death investigation systems** to provide adequate training, FP staffing, supporting staffing, and needed facilities, equipment, supplies, and budget to perform recommended procedures, consultations, and testing.
  - Completeness of investigations
  - Timeliness of results and reports
  - Care and counseling of family
- Provide financial incentives to enter FP workforce (shortage); encourage dual training in FP plus PP, NP, or CvP.

Synoptic Reporting

Workshop Presenter: Mary Ann Sens, MD., Ph.D.

Synoptic Reporting

- For deaths in which the cause of death cannot be determined, the autopsy report should contain:
  - At minimum, a synoptic report, including the following elements: cause of death, manner of death, investigation, medical history, sleep environment concerns, other environmental concerns, other objective concerns, autopsy, toxicology, ancillary studies, and radiologic studies, and;
  - Ideally, an organized, well-written summary section that details a rationale for the chosen cause of death statement, highlighting influential aspects of the history, investigation, or autopsy.

Why a Synoptic Report?

Challenges with Certification

- Rich and detailed investigation cannot be conveyed
- Data elements for public health / research not readily gathered
  - Poor surveillance tool for interventions, trends
- Wording on DC may totally change intent of certifier

Goals with Certification

- Wanted to convey some major scene / investigation points
- Wanted clarity in diagnosis and certification

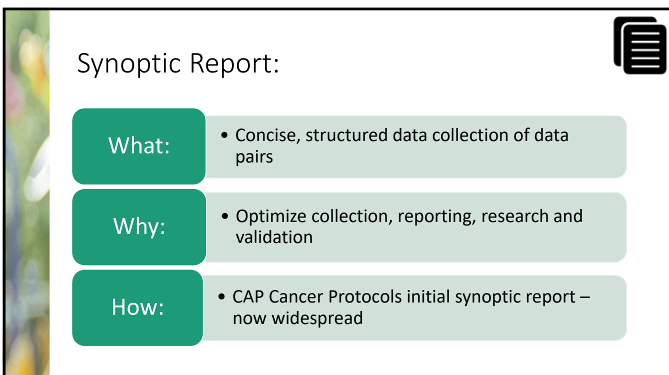
Why a Synoptic Report?

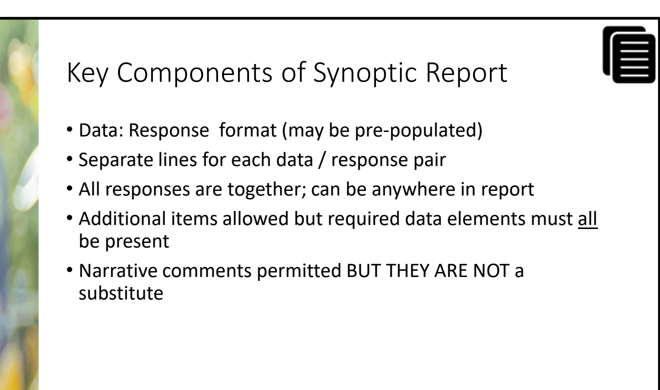
Desired Solution

- Certification terminology that CANNOT be incorrectly coded
- Certification that permits identification of areas for surveillance

- Report details of scene and autopsy findings
- Include level of investigation and testing

- Standardized certification choices
- Synoptic reporting of pediatric sudden deaths





Pathology Report Cancer Synoptic (for senior FP)

Final data pairs shown; may result from drop-down or other menu

CARCINOMA OF THE PROSTATE

TUMOR SUMMARY:	Prostate, prostatectomy
Procedure:	Radical Prostatectomy
Type:	Adenocarcinoma
Grade:	Gleason grade 3+4 = 7 (Group 3)
Gleason tertiary pattern:	Not applicable
Tumor size:	at least 1.1 cm as measured from the glass slide
Extraprostatic extension:	None
Urinary bladder neck invasion:	None
Seminal vesicle invasion:	None
Margins:	Positive, focal, left posterior
Treatment effect, primary site:	None
Lymph nodes, # sampled:	0
Stage (AJCC 8):	mpT2 pNX

Checklist – paper or within EMR

Gastrointestinal Stromal Tumor (GIST)

Based on AJCC/UICC TNM, 8th edition

Procedure
___ Local excision
_X_ Resection
Specify type (eg, partial gastrectomy): ____total gastrectomy_____
___ Metastasectomy
___ Other (specify): ___________________________
___ Not specified

Tumor Site
Specify (if known): __gastric body__________________
___ Not specified

Tumor Size
Greatest dimension: _5.3_ cm
*Additional dimensions: _4.8_ x _4.5_ cm
___ Cannot be determined (see "Comment")

Cannot have text only, even if all elements are present

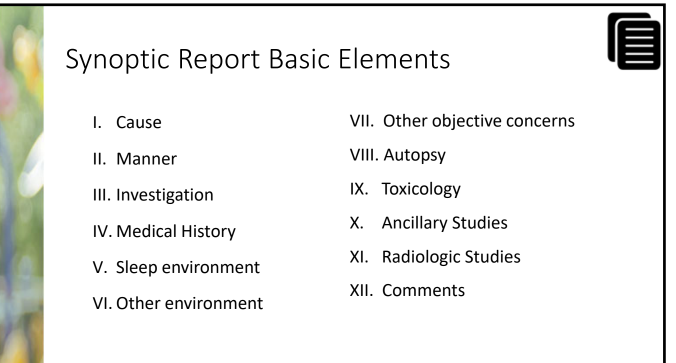
Kidney, Left (Radical Nephrectomy):

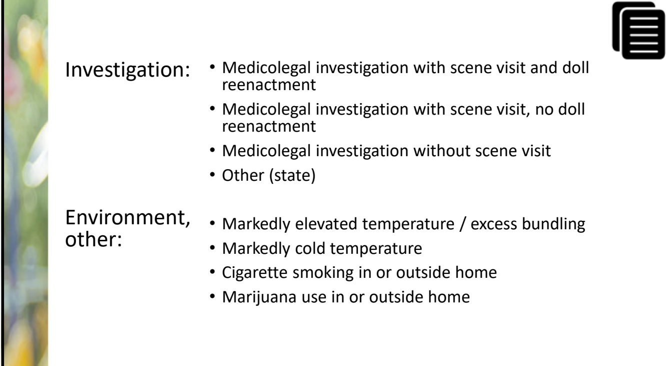
Clear cell adenocarcinoma, Furhman nuclear grade 3, 8.3 cm, unifocal involving upper pole of kidney and extending into the renal vein with the renal vein margin positive. Sarcomatoid features not identified.

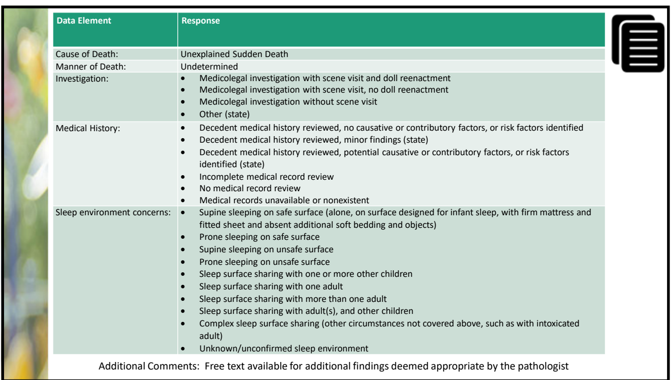
No lymph nodes submitted, adrenal gland uninvolved, lymphatic invasion present, no venous large vessel invasion, pT3, Nx. No significant pathologic alterations identified.

Application to Pediatric Sudden Death

- Good Death Investigation and Autopsy = Lots of Data
- Check list of elements to consider in investigation / autopsy
- Consistent data collection in standard reporting format
- Ability to assess detail of investigation and autopsy
- Proven ability of synoptic reports to improve quality

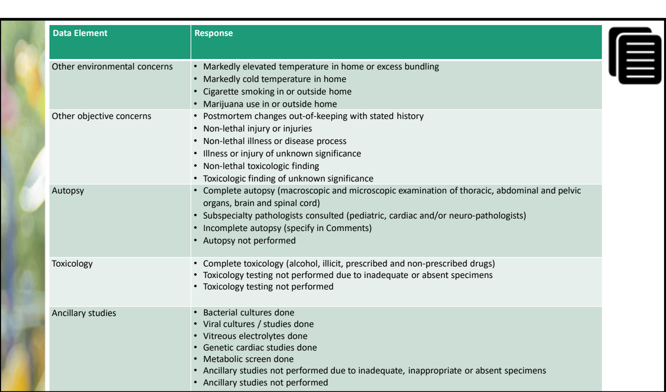






Data Element	Response
Cause of Death:	Unexplained Sudden Death
Manner of Death:	Undetermined
Investigation:	• Medicolegal investigation with scene visit and doll reenactment • Medicolegal investigation with scene visit, no doll reenactment • Medicolegal investigation without scene visit • Other (state)
Medical History:	• Decedent medical history reviewed, no causative or contributory factors, or risk factors identified • Decedent medical history reviewed, minor findings (state) • Decedent medical history reviewed, potential causative or contributory factors, or risk factors identified (state) • Incomplete medical record review • No medical record review • Medical records unavailable or nonexistent
Sleep environment concerns:	• Supine sleeping on safe surface (alone, on surface designed for infant sleep, with firm mattress and fitted sheet and absent additional soft bedding and objects) • Prone sleeping on safe surface • Supine sleeping on unsafe surface • Prone sleeping on unsafe surface • Sleep surface sharing with one or more other children • Sleep surface sharing with one adult • Sleep surface sharing with more than one adult • Sleep surface sharing with adult(s), and other children • Complex sleep surface sharing (other circumstances not covered above, such as with intoxicated adult) • Unknown/unconfirmed sleep environment

Additional Comments: Free text available for additional findings deemed appropriate by the pathologist



Data Element	Response
Other environmental concerns	• Markedly elevated temperature in home or excess bundling • Markedly cold temperature in home • Cigarette smoking in or outside home • Marijuana use in or outside home
Other objective concerns	• Postmortem changes out-of-keeping with stated history • Non-lethal injury or injuries • Non-lethal illness or disease process • Illness or injury of unknown significance • Non-lethal toxicologic finding • Toxicologic finding of unknown significance
Autopsy	• Complete autopsy (macroscopic and microscopic examination of thoracic, abdominal and pelvic organs, brain and spinal cord) • Subspecialty pathologists consulted (pediatric, cardiac and/or neuro-pathologists) • Incomplete autopsy (specify in Comments) • Autopsy not performed
Toxicology	• Complete toxicology (alcohol, illicit, prescribed and non-prescribed drugs) • Toxicology testing not performed due to inadequate or absent specimens • Toxicology testing not performed
Ancillary studies	• Bacterial cultures done • Viral cultures / studies done • Vitreous electrolytes done • Genetic cardiac studies done • Metabolic screen done • Ancillary studies not performed due to inadequate, inappropriate or absent specimens • Ancillary studies not performed

Outcomes of Synoptic Reporting

Certification clarity

- More standardized and accurate certification to allow INTENT of certifier to be accurately captured
- Improved surveillance opportunities and stratification of cases

Use / recognition of data gathered

- Evolution of synoptic reporting in a field
  - Verification of type, number of basic elements
  - Improve of choices of sub-data for clarity and actual use

Outcomes of Synoptic Reporting

Use and Improvements in Synoptic Reporting

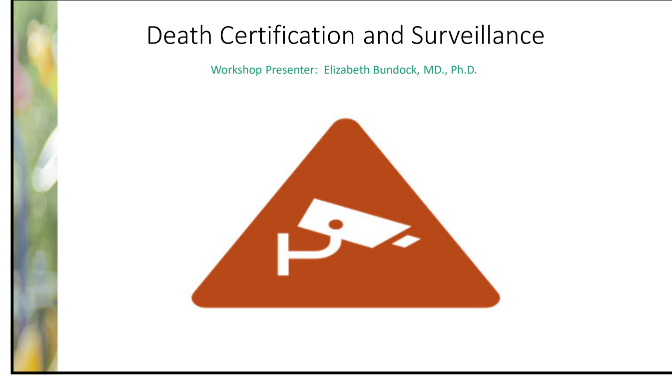
- Requires peer and expert review in quality process
- Requires investment by ultimate stakeholders – national organizations / members, public health, national demographic / statistical units (CDC, Census, NIH, HRSA, NIJ, others) for improving data accuracy and completeness

Current Procedural Guide and Considerations

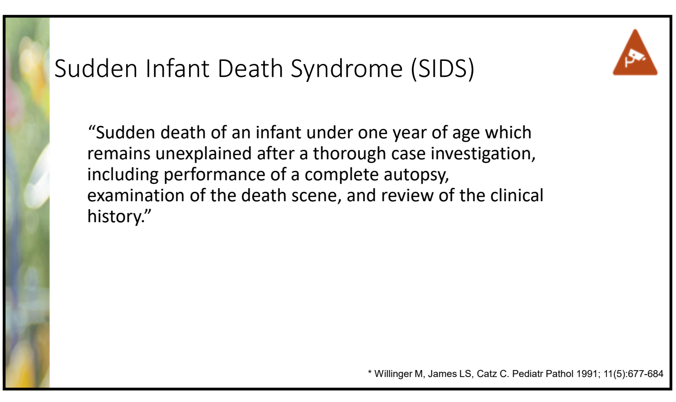
Deaths should be certified in consistent way to reflect accuracy and intent of certifier while maximizing surveillance opportunities

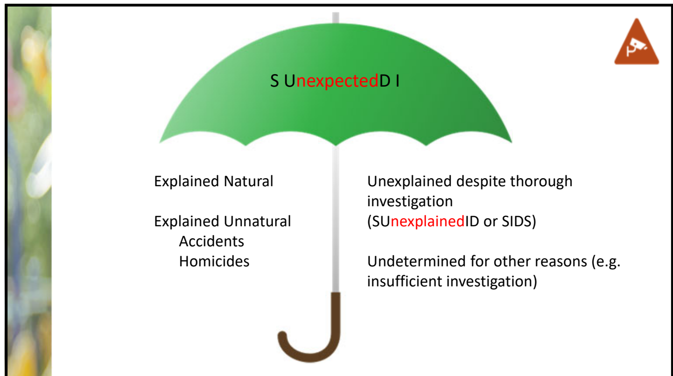
For deaths in which the cause of death cannot be determined, the autopsy report should contain:

- At minimum, a synoptic report, including the following elements: cause of death, manner of death, investigation, medical history, sleep environment concerns, other environmental concerns, other objective concerns, autopsy, toxicology, ancillary studies and radiologic studies
- Organized, well-written summary section that details a rationale for the chosen cause of death statement, highlighting the influential aspects of the history, investigation and autopsy


Death Certification and Surveillance
Workshop Presenter: Elizabeth Bundock, MD., Ph.D.

SUDI
SUID
Syndrome
Sudden
Undetermined
Unexplained
Infant
Unexpected
Investigation
Death
SUDI
SUDC
SIDS
Childhood


Sudden Infant Death Syndrome (SIDS)
"Sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history."
* Willinger M, James LS, Catz C. Pediatr Pathol 1991; 11(5):677-684



Inclusion of Risk Factors on DC

CAUSE OF DEATH (See instructions and examples)

32. **PART I.** Enter the chain of events--diseases, injuries, or complications--that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary.

Approximate interval: Onset to death

IMMEDIATE CAUSE (Final disease or condition ---------> resulting in death) a. Sudden Unexplained Infant Death

Due to (or as a consequence of):

Sequentially list conditions, if any, leading to the cause listed on line a. Enter the **UNDERLYING CAUSE** (disease or injury that initiated the events resulting in death) **LAST**

b. ______

Due to (or as a consequence of):

c. ______

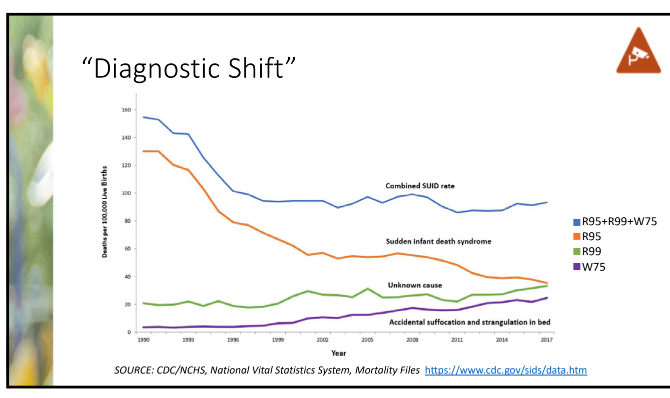
Due to (or as a consequence of):

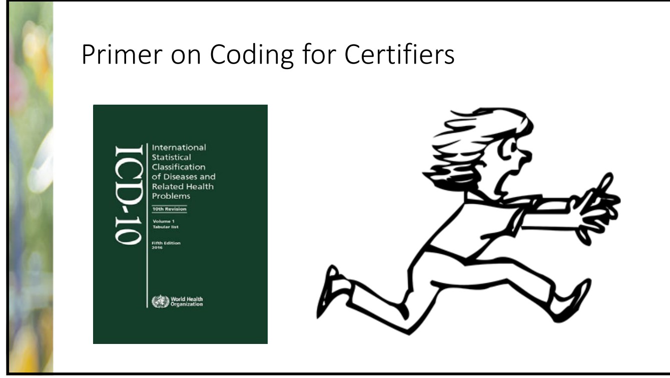
d. ______

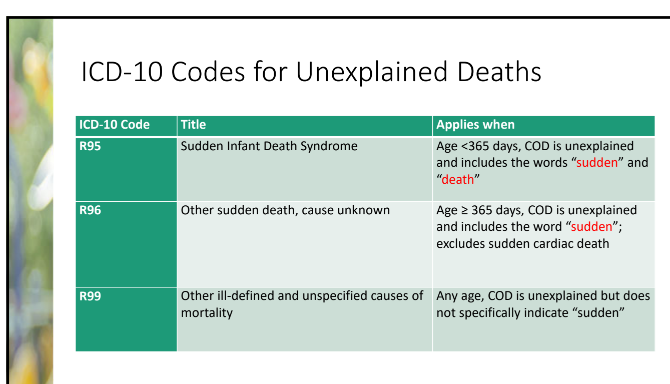
PART II. Enter other significant conditions contributing to death but not resulting in the underlying cause given in PART I

Sharing sleep surface with two adults

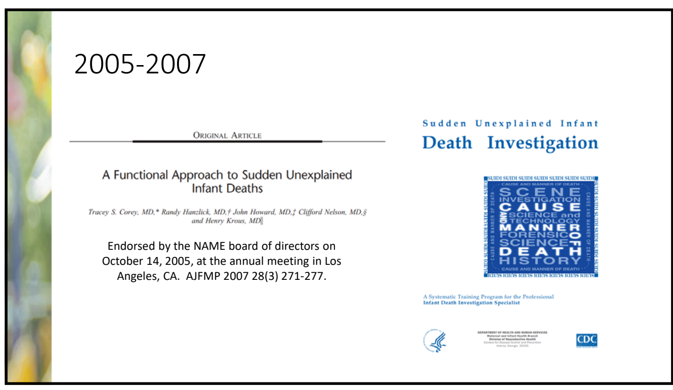
33. WAS AN AUTOPSY PERFORMED? ☐ Yes ☐ No







ICD-10 Code	Title	Applies when
R95	Sudden Infant Death Syndrome	Age <365 days, COD is unexplained and includes the words "sudden" and "death"
R96	Other sudden death, cause unknown	Age ≥ 365 days, COD is unexplained and includes the word "sudden"; excludes sudden cardiac death
R99	Other ill-defined and unspecified causes of mortality	Any age, COD is unexplained but does not specifically indicate "sudden"



Infants Certified with Sudden and Death

- If the cause of death is certified as any combination of "Sudden" and "Death"
  - sudden infant death syndrome,
  - sudden unexplained infant death, or
  - unexplained sudden death

and is not followed by a better-defined, coded condition in Part I,

the underlying cause code will be R95

Effect of Sequence and Part II on Coding When Cause of Death Includes "Sudden" and "Death"

Part I/COD, Line A	Due to Part I/COD, Line B	Part II/CCOD	ICD-10 Underlying Cause Code	Code Title
Sudden infant death syndrome OR Sudden unexplained infant death			R95	Sudden Infant Death Syndrome
"		Risk factors: Bed sharing, prone sleep	R95	Sudden Infant Death Syndrome
"	Possible asphyxia due to bed sharing		R95	Sudden Infant Death Syndrome

Effect of Sequence and Part II on Coding When Cause of Death Includes "Sudden" and "Death"

Part I/COD, Line A	Due to Part I/COD, Line B	Part II/CCOD	ICD-10 Underlying Cause Code	Code Title
Sudden infant death syndrome OR Sudden unexplained infant death	Possible overlay while bed sharing		W75	Accidental suffocation and strangulation in Bed
"		Possible overlay while bed sharing	R95	Sudden Infant Death Syndrome

Overlay will be used as the Underlying Cause when it appears in Part I, but not Part II.

Infant or Child Certified as COD: Undetermined

- If the cause of death is entered as "undetermined", the underlying cause code will be R99,

  except when another better-defined, coded condition is present.

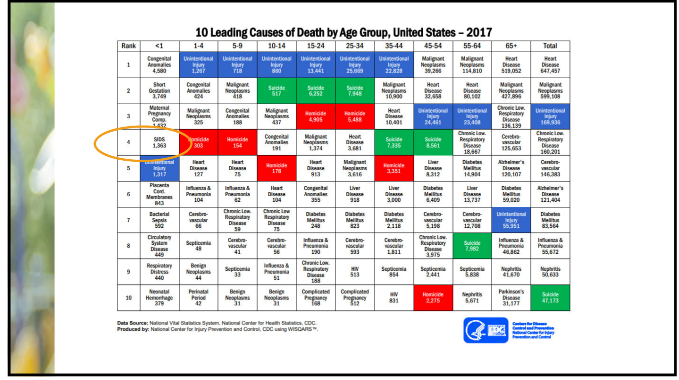
  In which case, "undetermined" is ignored and the Underlying Cause of Death will be coded according to the codable entity.

Effect of Part II on Coding When Cause of Death is "Undetermined"

Part I/COD	Part II/CCOD	ICD-10 Underlying Cause Code	Code Title
Undetermined		R99	Other ill-defined and unspecified causes of mortality
Undetermined	Risk factor: Bed sharing, Prone sleep	R99	Other ill-defined and unspecified causes of mortality
Undetermined	Risk factors: Bed sharing, Acute tracheitis	J041	Acute tracheitis

One Story, Three Codes

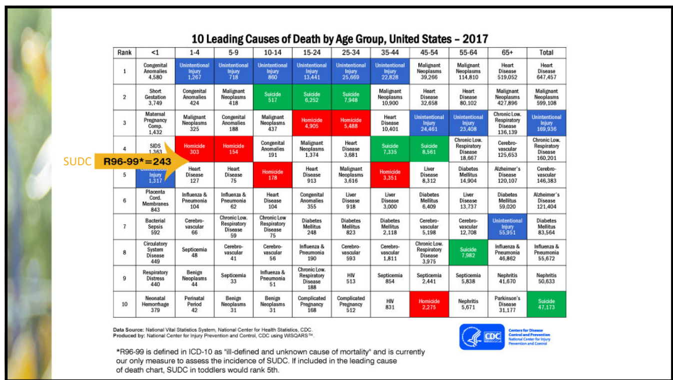
Part I/COD	Part II/CCOD	ICD-10 Underlying Cause Code	Code Title
Sudden infant death syndrome OR Sudden unexplained infant death	Possible asphyxia due to bed sharing	R95	Sudden Infant Death Syndrome
Undetermined	Risk factor: Bed sharing	R99	Other ill-defined and unspecified causes of mortality
Undetermined	Possible asphyxia due to bed sharing	W75	Accidental suffocation and strangulation in Bed



10 Leading Causes of Death by Age Group, United States – 2017

Rank	<1	1-4	5-9	10-14	15-24	25-34	35-44	45-54	55-64	65+	Total
1	Congenital Anomalies 4,580	Unintentional Injury 1,267	Unintentional Injury 718	Unintentional Injury 860	Unintentional Injury 13,441	Unintentional Injury 25,669	Unintentional Injury 22,828	Malignant Neoplasms 39,266	Malignant Neoplasms 114,810	Heart Disease 519,052	Heart Disease 647,457
2	Short Gestation 3,749	Congenital Anomalies 424	Malignant Neoplasms 418	Suicide 517	Suicide 6,252	Suicide 7,948	Malignant Neoplasms 10,900	Heart Disease 32,658	Heart Disease 80,102	Malignant Neoplasms 427,896	Malignant Neoplasms 599,108
3	Maternal Pregnancy Comp. 1,432	Malignant Neoplasms 325	Congenital Anomalies 188	Malignant Neoplasms 437	Homicide 4,905	Homicide 5,488	Heart Disease 10,401	Unintentional Injury 24,461	Unintentional Injury 23,408	Chronic Low. Respiratory Disease 136,139	Unintentional Injury 169,936
4	SIDS 1,363	Homicide 303	Homicide 154	Congenital Anomalies 191	Malignant Neoplasms 1,374	Heart Disease 3,681	Suicide 7,335	Suicide 8,561	Chronic Low. Respiratory Disease 18,667	Cerebro-vascular 125,653	Chronic Low. Respiratory Disease 160,201
5	Unintentional Injury 1,317	Heart Disease 127	Heart Disease 75	Homicide 178	Heart Disease 913	Malignant Neoplasms 3,616	Homicide 3,351	Liver Disease 8,312	Diabetes Mellitus 14,904	Alzheimer's Disease 120,107	Cerebro-vascular 146,383
6	Placenta Cord. Membranes 843	Influenza & Pneumonia 104	Influenza & Pneumonia 62	Heart Disease 104	Congenital Anomalies 355	Liver Disease 918	Liver Disease 3,000	Diabetes Mellitus 6,409	Liver Disease 13,737	Diabetes Mellitus 59,020	Alzheimer's Disease 121,404
7	Bacterial Sepsis 592	Cerebro-vascular 66	Chronic Low. Respiratory Disease 59	Chronic Low Respiratory Disease 75	Diabetes Mellitus 248	Diabetes Mellitus 823	Diabetes Mellitus 2,118	Cerebro-vascular 5,198	Cerebro-vascular 12,708	Unintentional Injury 55,951	Diabetes Mellitus 83,564
8	Circulatory System Disease 449	Septicemia 48	Cerebro-vascular 41	Cerebro-vascular 56	Influenza & Pneumonia 190	Cerebro-vascular 593	Cerebro-vascular 1,811	Chronic Low. Respiratory Disease 3,975	Suicide 7,982	Influenza & Pneumonia 46,862	Influenza & Pneumonia 55,672
9	Respiratory Distress 440	Benign Neoplasms 44	Septicemia 33	Influenza & Pneumonia 51	Chronic Low. Respiratory Disease 188	HIV 513	Septicemia 854	Septicemia 2,441	Septicemia 5,838	Nephritis 41,670	Nephritis 50,633
10	Neonatal Hemorrhage 379	Perinatal Period 42	Benign Neoplasms 31	Benign Neoplasms 31	Complicated Pregnancy 168	Complicated Pregnancy 512	HIV 831	Homicide 2,275	Nephritis 5,671	Parkinson's Disease 31,177	Suicide 47,173

Data Source: National Vital Statistics System, National Center for Health Statistics, CDC.
Produced by: National Center for Injury Prevention and Control, CDC using WISQARS™.



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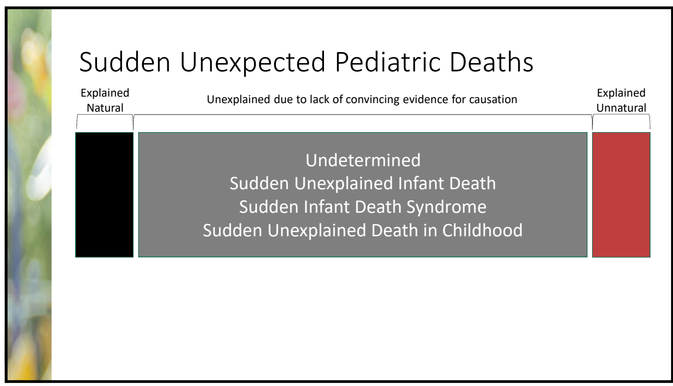
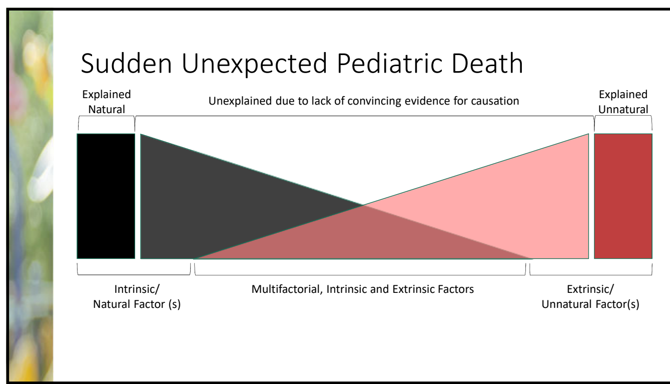
Data Source: National Vital Statistics System, National Center for Health Statistics, CDC.
Produced by: National Center for Injury Prevention and Control, CDC using WISQARS™.

*R96-99 is defined in ICD-10 as "ill-defined and unknown cause of mortality" and is currently our only measure to assess the incidence of SUDC. If included in the leading cause of death chart, SUDC in toddlers would rank 5th.



Sudden Unexpected Pediatric Death



Death Certification and Surveillance

- When cause of death cannot be determined, one of the following cause statements are recommended as applicable :
  - Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors).
  - Unexplained Sudden Death (Intrinsic Factors Identified).
  - Unexplained Sudden Death (Extrinsic Factors Identified).
  - Unexplained Sudden Death (Intrinsic and Extrinsic Factors Identified).
  - Undetermined (Not further specified).
  - Undetermined (Insufficient Data).

Intrinsic Factors

- natural conditions or risk factors associated with abnormal physiology or anatomy that are concerning as contributors to death but are insufficient as a cause
  - (e.g. low birth weight, preterm birth, small for gestational age, concurrent non-lethal illness, history of febrile seizures),
- or natural conditions of unknown significance
  - (e.g. cardiac channelopathy or seizure gene variants of unknown significance).

Extrinsic Factors

- conditions in the child's immediate environment that are a potential threat to life but cannot be deemed the cause of death with reasonable certainty,
  - (e.g. side or prone sleep if unable to roll to supine, over-bundling without documented hyperthermia, objects in immediate sleep environment, sleep environment not specifically designed for infant sleep, soft or excessive bedding, and sleep-surface sharing),
- injuries or toxicologic findings that are either non-lethal or of unknown lethality, or
- circumstances/findings otherwise concerning for unnatural death.

COD: Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors)

Criteria for Infants:

1. Infant less than one year of age in apparent good health that dies suddenly and unexpectedly.
2. For Sleep Related Deaths:
   a) Placed alone, supine, in infant-specific sleep environment (e.g. crib, bassinet, portable crib, play pen) with flat, firm sleep surface, uncluttered by objects, and without potential areas of entrapment.
   b) Found unresponsive or dead, in the same sleep environment, with no obstruction of the nose and/or mouth or compression of neck/chest to cause asphyxia given the developmental abilities of the infant, as described by finder and demonstrated by doll reenactment.
3. The infant was not overly dressed or bundled for the environmental temperature.
4. Competent caregiver not impaired by drugs or alcohol.
5. Physical findings on body and at scene consistent with history provided by caregiver.

6. Completion of scene investigation and doll reenactment unless caregiver declines.
7. Review of child medical records and family health history.
8. Complete autopsy with histology, comprehensive toxicology testing (including vitreous chemistries if possible), and skeletal survey.
9. No anatomic, metabolic, toxicologic, chemical, historical, or external cause of death identified. Genetic testing is recommended but not required for this certification.
10. No extrinsic or intrinsic risk factors are identified.

COD: Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors)

Criteria for Children greater than 12 months of age:

1. Child greater than 12 months of age in apparent good health that dies suddenly and unexpectedly.
2. For sleep related deaths: Found unresponsive or dead, with no obstruction of the nose and/or mouth or compression of neck/chest considered sufficient to cause asphyxia given the developmental abilities of the child (prone position without obstruction of nose and/or mouth may be present).
3. Physical findings on body and at scene consistent with history provided by caregiver.
4. Competent caregiver not impaired by drugs or alcohol.
5. Completion of scene investigation and doll reenactment if age or circumstance appropriate and caregiver cooperative.
6. Review of child medical records and family health history.
7. Complete autopsy with histology, comprehensive toxicology testing of blood (including vitreous chemistries if possible).
8. No anatomic, metabolic, toxicologic, chemical, historical or external cause of death identified. Genetic testing is recommended but not required for this certification.
9. No extrinsic or intrinsic risk factors are identified.

COD: Unexplained Sudden Death (Intrinsic Factors Identified)

A cause of death cannot be determined and criteria for Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors) are not met due to

- intrinsic/natural abnormalities that are either known risk factors for sudden death

(including, but not limited to, low birth weight, preterm birth, small for gestational age, concurrent non-lethal illness, febrile seizures)

- or are of unknown significance (including, but not limited, to mutations of unknown significance).
- Trauma and other unnatural etiologies are sufficiently excluded.

COD: Unexplained Sudden Death (Extrinsic Factors Identified)

A cause of death cannot be determined and criteria for Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors) are not met due to

- the presence of unintentional extrinsic factors that increase risk for unnatural death.
  - For infants this includes, but is not limited to, side or prone sleep if unable to roll to supine, overheating, objects in sleep environment, infant in sleep environment not specifically designed for infant sleep, soft or excessive bedding, and sleep-surface sharing.
  - At all pediatric ages this may include, but is not limited to, non-lethal injuries or injuries of unknown significance, non-lethal toxicologic findings of unknown significance, or circumstances otherwise concerning for unnatural death.

COD: Unexplained Sudden Death (Intrinsic and Extrinsic Factors Identified)

A cause of death cannot be determined and criteria for Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors) are not met due to

- a combination of intrinsic and extrinsic factors as described above.

COD: Undetermined (Not further specified)

A cause of death cannot be determined due to circumstances or findings that make the above classifications inapplicable.

- Examples may include
  - Inconsistent histories and/or other evidence that raise uncertainty about manner of death,
  - Competing causes of death
  - Cases which remain undetermined but were not sudden.

COD: Undetermined (Insufficient Data):

A cause of death cannot be determined because

- investigation, death scene examination, or autopsy were substantially limited, incomplete, or insufficient.

Examples may include

- legal/religious restrictions
- delayed report of death that limits scene investigation,
- decomposition.

Death Certification and Surveillance

- The following criteria for certification of an infant death as being caused by an asphyxia etiology are recommended:
  - The case must have a complete/full autopsy.
  - Toxicology, histology, vitreous electrolytes, cultures, and review of medical history are to be performed, as necessary as determined by investigation and autopsy.
  - The infant must have obstruction of both nose and mouth or compression of the neck or chest, that is reliably witnessed or demonstrated by doll reenactment, or other reliable evidence of overlay or entrapment.
  - Asphyxiation must be probable given infant's age and stage of development.
  - There cannot be a reasonable competing cause of death.

Death Certification and Surveillance

R95 or R96 depending on age on certificate**

Unexplained Sudden Death (No Identified Intrinsic or Extrinsic Factors).
Unexplained Sudden Death (Intrinsic Factors Identified).
Unexplained Sudden Death (Extrinsic Factors Identified).
Unexplained Sudden Death (Intrinsic and Extrinsic Factors Identified).

R99

Undetermined (Not further specified).
Undetermined (Insufficient Data).

**To better represent the current and future data captured by R95/MH11, it is recommended that the title of this code be changed to "Unexplained Sudden Death in Infancy or Sudden Infant Death Syndrome."

Development of extension codes by the NCHS to capture data included within parentheses is recommended.

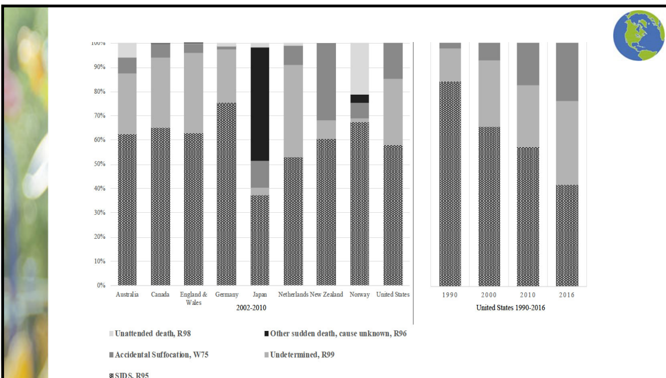
The 3rd International Congress on Sudden Death in Infants and Children

Workshop Presenter: Richard D. Goldstein, MD.

ICD-10 Codes

R95 Sudden Infant Death Syndrome
R96 Other sudden death, cause unknown
(recommended code for SUDC)
R99 Ill-defined and unknown cause of mortality
W75 Accidental suffocation and strangulation in bed

ICD-11 being finalized (MH11, MH12, MH14, PB00-PB0Z)

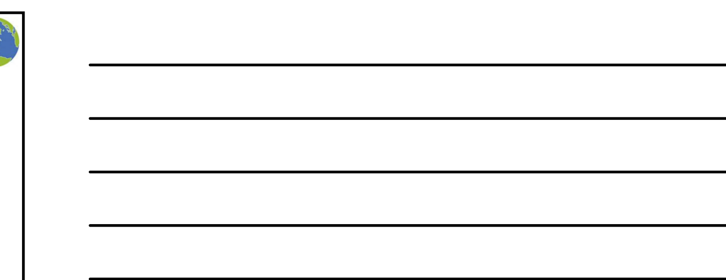


Accommodations by WHO Certifiers

R95 (SIDS):
Deaths under 1 year with the following inclusion terms:
Cot death, Crib death, SDII, SID, SIDS, SUD, SUDI, SUID
Sudden (unexpected) (unattended) (unexplained), death (cause unknown) (in infancy)(syndrome), infant death (syndrome)

R96 (intended SUDC):
Deaths 1 year of age and older with all the above inclusion terms
Coded to Instantaneous Death - R96.0

BUT: Undetermined with *possible* asphyxia, or risk in sleep environment, etc. will elevate to ASSB **W75**



The 3rd International Congress on Sudden Death in Infants and Children
Radcliffe Institute for Advanced Study, Harvard University
Robert N. Anderson, PhD, National Center for Health Statistics, North American Collaborating Centre for the WHO Family of International Classifications, Hyattsville, MD, USA
Peter S. Blair, PhD, University of Bristol, International Society for the Study and Prevention of Perinatal and Infant Death, UK
Elizabeth A. Bundock, MD, PhD, Office of the Chief Medical Examiner, National Association of Medical Examiners, Vermont, USA
Laura G. Crandall, SUDC Registry and Research Collaborative, New York University Langone Medical Center, New York, NY, USA
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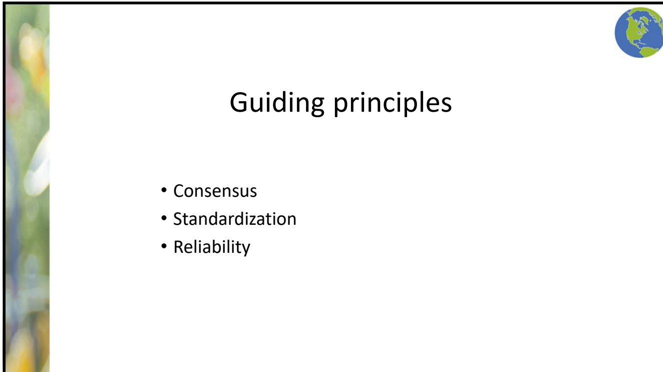
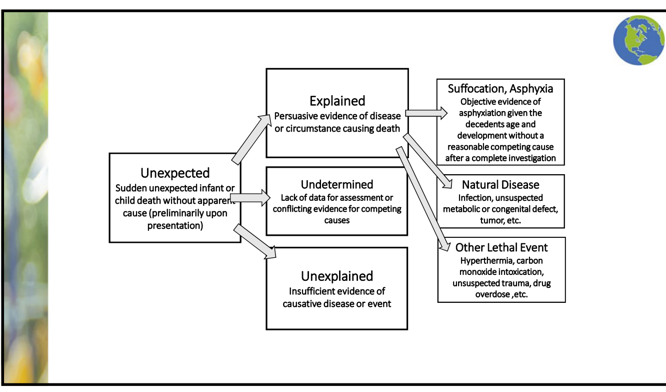
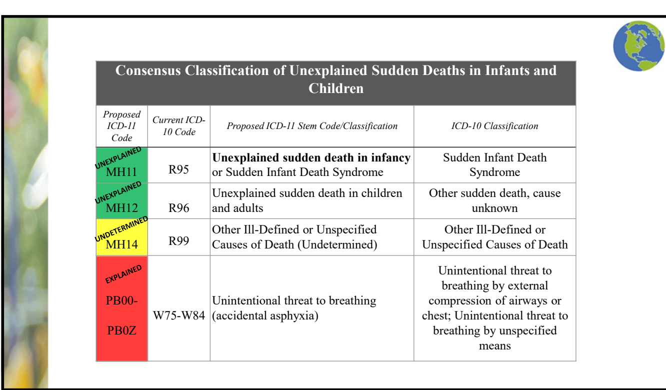
Barbara A. Sampson, MD, PhD, Chief Medical Examiner, New York, NY, USA
Mark Super, MD, Merced County Sheriff - Coroner's Office, CA, USA


Guiding principles
• Consensus
• Standardization
• Reliability


Unexpected
Sudden unexpected infant or child death without apparent cause (preliminarily upon presentation)
Explained
Persuasive evidence of disease or circumstance causing death
Undetermined
Lack of data for assessment or conflicting evidence for competing causes
Unexplained
Insufficient evidence of causative disease or event
Suffocation, Asphyxia
Objective evidence of asphyxiation given the decedents age and development without a reasonable competing cause after a complete investigation
Natural Disease
Infection, unsuspected metabolic or congenital defect, tumor, etc.
Other Lethal Event
Hyperthermia, carbon monoxide intoxication, unsuspected trauma, drug overdose ,etc.

3 Categories

- **Undetermined** because you don't have enough to make a conclusion
- **Explained** by evidence that is not circumstantial or based only on risk **Thorough and Conclusive**
  - Persuasive evidence of lethality
- **Unexplained** after a credible, realistic process **Thorough and Conclusive**



Consensus Classification of Unexplained Sudden Deaths in Infants and Children

Proposed ICD-11 Code	*Current ICD-10 Code*	*Proposed ICD-11 Stem Code/Classification*	*ICD-10 Classification*
UNEXPLAINED MH11	R95	**Unexplained sudden death in infancy** or Sudden Infant Death Syndrome	Sudden Infant Death Syndrome
UNEXPLAINED MH12	R96	Unexplained sudden death in children and adults	Other sudden death, cause unknown
UNDETERMINED MH14	R99	Other Ill-Defined or Unspecified Causes of Death (Undetermined)	Other Ill-Defined or Unspecified Causes of Death
EXPLAINED PB00-PB0Z	W75-W84	Unintentional threat to breathing (accidental asphyxia)	Unintentional threat to breathing by external compression of airways or chest; Unintentional threat to breathing by unspecified means

MH11: Unexplained sudden death in infancy or SIDS

The sudden *unexpected* death of an apparently healthy infant under one year of age that *remains unexplained* after a thorough case investigation, including performance of a complete autopsy with ancillary testing, examination of the death scene, and review of the clinical history. (based upon NAME)

MH12: Unexplained sudden death in children and adults

The sudden unexpected death of a person *one year of age or older* that remains unexplained after a thorough case investigation, including performance of a complete autopsy with ancillary testing, and review of the clinical history and circumstances of death.

MH14: Other Ill-Defined or Unspecified Causes of Death (Undetermined)

Cases may be certified as Undetermined when:

1. The investigation, death scene examination, or autopsy was *substantially limited, incomplete or insufficient*, for example legal/religious restrictions, delayed report of death that limits scene investigation, or decomposition; or
2. Inconsistent accounts or other findings raise *competing conclusions* about the cause of death.

PB00-PB0Z: Unintentional threat to breathing (accidental asphyxia)

Certification of asphyxia: Adequate evidence must be documented to substantiate asphyxiation, given the decedent's age and stage of development. There cannot be a reasonable competing cause of death after a complete autopsy with ancillary testing, examination of the death scene (with a doll re-enactment when appropriate), and review of the clinical history.

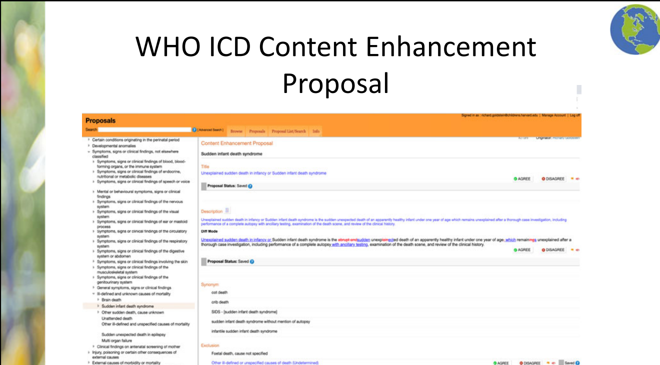
In infants, bed/sleep surface sharing, soft bedding, or prone sleep, without adequate evidence for airway obstruction or chest wall compression, are insufficient to certify a death as due to asphyxia. These deaths may be more appropriately certified as unexplained sudden death or SIDS. The use of "possible" or "probable" asphyxia will result in the death being classified as asphyxia.

Rises to the level of *Explained*

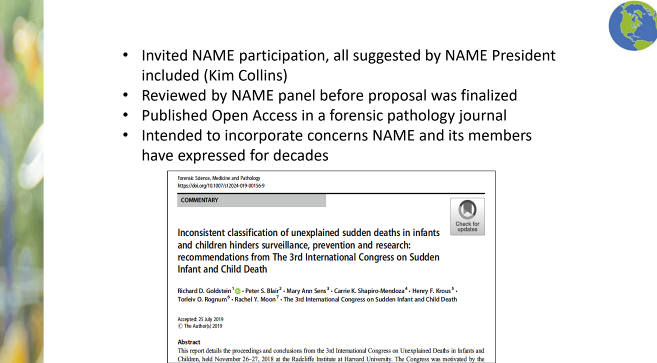
Implications

- Global reliability and standardization
- Thorough careful work is reflected in the “unexplained” diagnosis
- Lack of resources and variable standards are reflected in “undetermined”
  - Frustrated assessments
  - Accurate portrayal that insufficient resources can limit assessments
- Explanation is not the presence of risk but an *assessment of the lethality* of those factors in an individual case
- Legitimate conclusion of asphyxia is clearly stated

WHO ICD Content Enhancement Proposal



- Invited NAME participation, all suggested by NAME President included (Kim Collins)
- Reviewed by NAME panel before proposal was finalized
- Published Open Access in a forensic pathology journal
- Intended to incorporate concerns NAME and its members have expressed for decades



Forensic Science, Medicine and Pathology
https://doi.org/10.1007/s12024-019-00156-9

COMMENTARY

Check for updates

Inconsistent classification of unexplained sudden deaths in infants and children hinders surveillance, prevention and research: recommendations from The 3rd International Congress on Sudden Infant and Child Death

Richard D. Goldstein[1] · Peter S. Blair[2] · Mary Ann Sens[3] · Carrie K. Shapiro-Mendoza[4] · Henry F. Krous[5] · Torleiv O. Rognum[6] · Rachel Y. Moon[7] · The 3rd International Congress on Sudden Infant and Child Death

Accepted: 25 July 2019
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Abstract
This report details the proceedings and conclusions from the 3rd International Congress on Unexplained Deaths in Infants and Children, held November 26–27, 2018 at the Radcliffe Institute at Harvard University. The Congress was motivated by the

Family Needs & Professional Relations

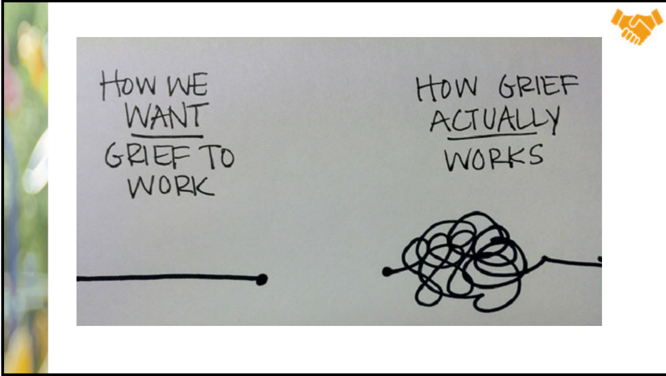
Guidance for Professional Relations

- Establish trauma-informed inter-agency care protocols
- Training for first response teams
- Education for hospital teams about the local medicolegal death investigation system
- Medical Training
  - Multidisciplinary approach
  - Access for Debriefings/Panel Discussions
  - Develop Network of Suitable Consultants
- Role of child death review committees

Family Needs & Professional Relations

Grief

- Parental Bereavement- Hardest of Losses to Bear
- In the Blink of an Eye
- First 72 Hours is Chaos for Families
  - Confusion, lack of control…
  - Multiple Agencies/Professionals Involved- none of their choosing
- What does it look like?
  - 5 Stages: Denial, Anger, Bargaining, Depression and Acceptance
  - Or…



Procedural Guidelines for Family Needs

- To prevent further trauma, complete thorough investigations and foster positive outcomes
- Maintain an unbiased, non-accusatory approach to parents
- Respect for privacy, dignity, and comfort for families
- Opportunity to see and hold the infant in supervised conditions once death has been pronounced and before transport.
- Timely communication associated with positive long-term bereavement outcomes
- Open communication with MDI and single point of contact for families
  - Information in multiple formats - written (Help For Families Brochure), verbal, through clinicians, etc.

Procedural Guidelines for Family Needs

- Provide services or referrals to address
  - Grief support for surviving family members
  - Medical follow-up (Cardiac/Genetic consults etc.) and related referrals (as clinically indicated by investigation)
  - Home Visits
- Opportunity for Post-autopsy conference with family members and stakeholders/clinicians
- Investigation becomes part of each family's history

Family Needs & Professional Relations

- INSERT VIDEO

We are what we repeatedly do.
Excellence, then, is not an act, but a habit.
~ **Aristotle**

It always seems impossible until it is done.
~ **Nelson Mandela**

Thank you!

- All committee members who donated their time and expertise to see this project to completion
- SUDC Foundation for grant support for this project, the ability to publish the book and to provide complimentary copies to all NAME members
- NAME for administrative and organizational support.
- American Academy of Pediatrics for organizational support.
- Academic Forensic Pathology for the opportunity to publish this work in a volume adequate to address the complexity and depth of the issues.