CDC’s Sudden, Unexpected Infant Death Initiative

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Keeping Kids Alive
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Presentation outline

• Definitions
• SUID Trends
• Importance of Case Investigation
• CDC’s SUID Initiative
• SUID Case Registry
• Partners
Definitions
SUID definition

- SUID = sudden, unexpected infant death

- Infant deaths that:
  - Occur suddenly and unexpectedly
  - Have no obvious manner and cause of death prior to investigation

- Excludes deaths with an obvious cause, e.g., motor vehicle accidents
SUID and its subtypes

- SIDS
- Accidental suffocation
- Unknown
- Poisoning
- Metabolic disorders
- Hypothermia/Hyperthermia
- Neglect or homicide
SUID

**Explained**
- Poisoning
- Head injury
- Metabolic disorder
- Neglect or homicide
- Hypo or hyperthermia
- Accidental suffocation??

**Unexplained**
- SIDS
- Cause unknown or unspecified
- SIDS, but cannot rule out suffocation from unsafe sleep environment
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.”

ICD diagnostic codes for selected SUID

<table>
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<tbody>
<tr>
<td>ASSB</td>
<td>E913.0</td>
<td>W75</td>
</tr>
<tr>
<td>SIDS</td>
<td>798.0</td>
<td>R95</td>
</tr>
<tr>
<td>Unknown cause</td>
<td>799.9</td>
<td>R99</td>
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ICD: International Statistical Classification of Diseases and Related Health Problems
NCHS definition of SIDS for coding purposes

- Sudden Death in Infancy or SDII
- Sudden Infant Death or SID
- Sudden Infant Death Syndrome or SIDS
- Sudden Unexplained Death or SUD
- Sudden Unexplained (Unexpected) Death in Infancy or SUDI
- Sudden Unexplained Infant Death or SUID
- Sudden plus (unexpected) or (unattended) or (unexplained)
- Death plus (cause unknown) or (in infancy) or (syndrome)
- Infant death plus (syndrome)
- Presumed SIDS
- Probably SIDS
- Consistent with SIDS
- Cot Death or Crib Death
Examples of deaths coded as ASSB

- Suffocation by soft bedding, pillow, waterbed mattress
- Overlaying (rolling on top of or against baby while sleeping)
- Wedging or entrapment between mattress and wall, bed frame, furniture
- Strangulation (infant’s head and neck caught between crib railings)
Why be concerned about SUID?

- **SUID**
  - ~ 4600 per year
  - Rates comparable to birth defects mortality
  - About 2500 of these are SIDS

- **SIDS**
  - Leading cause of post-neonatal mortality
  - Third leading cause of all infant mortality

- **Accidental suffocation & strangulation in bed**
  - Rates have more than tripled in last decade
  - 3.7 to 12.5 deaths per 100,000 live-births from 1995 to 2005

- **Potentially preventable infant mortality**
SUID Trends
Mortality rates due to SIDS
U.S. 1980-2004

Rate per 100,000 live births

Year


160 150 140 130 120 110 100 90 80 70 60 50 40 30 20 10 0
Changing trends

• Decline in SIDS is offset by increasing rates of:
  – Unknown cause
  – ASSB

• This change in classification can be explained by:
  – How investigations are conducted
  – How diagnoses are made

Shapiro-Mendoza CK et al, Pediatrics, 2009
Infant mortality rates due to SIDS, ASSB plus cause unknown, and combined SUID, United States, 1990-2005

Source: CDC WONDER, Mortality Files
Proportionate SUID mortality, United States, 1990-2004
Reason for change in trends

• The way medical examiners and coroners report these deaths seems to be changing
  – Moving away from SIDS as a diagnosis
  – Reporting more suffocation

• Reason unknown, but possibly related to...
  – Better and more thorough investigations
  – Stricter adherence to 1991 SIDS definition
  – Increase in child death reviews

Why be concerned about changes in reporting practices?

- Many SUID are not investigated
- Even if investigated, cause-of-death data are not collected and reported consistently
- This hinders our ability to monitor national trends, identify risk factors, or evaluate intervention programs
- If we want to reduce these infant deaths, we need valid and reliable data to support our research and prevention efforts
Importance of the Case Investigation
Importance of a case investigation

- Determine accurate cause and manner of death
- Differentiate between causes of SUID
- Improve validity and reliability of data
  - Monitor trends in SUID
  - Conduct research to identify risk factors
  - Design interventions to prevent SUID
  - Evaluate programs aimed at prevention
Components of a comprehensive case investigation

• Thorough death scene investigation
  – Scene photos
  – Doll reenactment
  – Completion of SUIDI RF

• Complete Autopsy
  – Toxicology, histology, radiology, etc.

• Review of maternal and infant medical records
  – Identify possible biologic risks

All completed and available to ME/C before determining cause and manner of death
Systems influencing reporting and classification

**Best Case Scenario**
- SUIDIRF Photos Dolls
- Complete autopsy
- Proper wording & coding
- Has all info needed

**Worst Case Scenario**
- No data collected
- ‘Visual’ autopsy
- Mis-worded & mis-coded
- Does not have all info

**Sudden Unexpected Infant Death**
- Death Scene Investigation
- Medical Examiner/Coroner/Pathologist
- Death Certificate
- Child Death Review
- SUID Case Registry
A major increase in the capture of SUIDI information will depend on changes in death scene investigation protocols and/or their implementation. We found that much of the requested SUIDI information was just not available in existing documentation.

-- SUID Feasibility Study Report, 2007
CDC’s SUID Initiative and Activities
Goals of the CDC’s SUID Initiative

• Standardize and improve data collected at death scene
• Promote consistent diagnosis of cause of death
• Improve national reporting of SUID
• Prevent SUID by using improved data to identify those at risk
SUID Initiative main activities

• Revise the 1996 death scene investigation form
• Develop training curriculum and materials
• Disseminate the SUIDI Reporting Form and the training curriculum and materials
• Promote the use of the SUIDI Reporting Form and the training curriculum and materials
• Evaluate the impact of the SUIDI Training Academies
• Conduct a pilot SUID case registry project
SUID Initiative main activities

Revise the 1996 Sudden, Unexplained Infant Death Investigation Reporting Form (SUIDIRF) and guidelines

- Formed a national workgroup
- Evaluated form and field testing was positive
2006 SUIDI Reporting Form

**INVESTIGATION DATA**

- **Infant's Information:**
  - Last
  - First
  - M.
  - Case #
  - Sex: [ ] Male [ ] Female
  - Date of Birth: [Month] [Day] [Year]
  - Age: [Month] [Day] [Year]
- **Race:** [ ] White [ ] Black [ ] African Am. [ ] Asian [ ] Pacific Islander [ ] Native Am. [ ] Indian [ ] Hispanic [ ] Latino [ ] Other
- **Infant's Primary Residence Address:**
  - Address
  - City
  - County
  - State
  - Zip
- **Incident Address:**
  - Address
  - City
  - County
  - State
  - Zip
- **Contact Information for Witness:**
  - Relationship to the deceased: [ ] Birth Mother [ ] Birth Father [ ] Adoptive or Foster Parent [ ] Physician [ ] Grandmother [ ] Grandfather [ ] Other:
  - Last Name
  - First Name
  - M.
  - SS #: [ ]
  - Home Address: City
  - State
  - Zip
  - Place of Work: City
  - State
  - Zip
  - Phone (H): [ ] Phone (W): [ ] Date of Birth: [Month] [Day] [Year]

**WITNESS INTERVIEW**

1. **Are you the usual caregiver?** [ ] Yes [ ] No
2. **Tell me what happened:**
   - [ ]
3. **Did you notice anything unusual or different about the infant in the last 24 hrs?** [ ] Yes [ ] No
   - Describe:
4. **Did the infant experience any falls or injury within the last 72 hrs?** [ ] Yes [ ] No
   - Describe:
5. **When was the infant LAST PLACED?**
   - [Month] [Day] [Year]
   - Location (room)
6. **When was the infant LAST KNOWN ALIVE/LIVING?**
   - [Month] [Day] [Year]
   - Location (room)
7. **When was the infant FOUND?**
   - [Month] [Day] [Year]
   - Location (room)
8. **Explain how you knew the infant was still alive:**
   - [ ]
9. **Where was the infant (P)laced, (L)ast known alive, (F)ound (circle P, L, or F in front of appropriate response):**
   - P: [ ] L: [ ] F: [ ]
   - Bedside co-sleeper [ ] Cradle [ ] Mattress/box spring [ ] Soft/toothbrush [ ] Other [ ]
   - Car seat [ ] Crib [ ] Mattress on floor [ ] Swing [ ] Other [ ]
   - Chair [ ] Floor [ ] Playpen [ ] Portable crib [ ] Waterbed [ ]
SUID Initiative main activities

Develop training curriculum and materials

- Convened a national steering committee to plan training content and give endorsement
- Convened a national work group of experts with experience conducting scene investigations and infant death review to write training curriculum materials
Academy curriculum

Academy participants are trained to:

• Properly complete the revised SUIDI reporting form
• Recognize stages of infant growth and development
• Interview (vs. interrogate) family/witnesses at scene
• Differentiate SIDS, suffocation, and other sudden deaths
• Create scene reenactments and take photos
• Conduct a comprehensive death scene investigation
• Classify SUID death and fill out a death certificate
Sudden, Unexplained Infant Death Investigation

curriculum guide
SUIDI scene guidelines
Sudden Unexplained Infant Death Investigation

A Systematic Training Program for the Professional Infant Death Investigation Specialist
SUID Initiative main activities

Disseminate the SUIDI Reporting Form and the training curriculum and materials

- Conduct 5 regional train-the-trainer academies
- Train multidisciplinary teams of 5 from each state
SUIDI Training Academies

• Beginning in 2006, 5 member teams from each state (plus DC and 2 Indian Nations) attended training

• Participants were medical examiners/coroners, law enforcement, educators, child advocates and death scene investigators

• Train the trainer format

• The training took place over 3.5 days
SUIDI Training Academy team members

- Medical examiner or coroner
- Law enforcement
- Death scene investigator
- Post secondary teacher
- Child advocate
Training accomplishments

• 357 train-the-trainers at pilot training
• 275 train-the-trainers at 5 regional academies
• 50 state teams trained, 1 in each of 50 states
• 14,456 secondary participants trained to date
  – 11,026 at state and local conferences, academies, workshops
  – 3,430 participants at 22 different sites in 11 states
SUID Initiative main activities

Promote the use of the SUIDIRF and training materials
Endorsements

• National Sheriff’s Association
• National Association of Medical Examiners
• American Board Medicolegal Death Investigators
• International Associations of Coroners and Medical Examiners
CDC’s SUID Case Registry
What is a case registry?

- Ongoing, systematic collection, analysis, interpretation, and dissemination of data about a health-related event
- Used for public health action to reduce morbidity and mortality and to improve health

CDC. Updated guidelines for evaluating public health surveillance systems: recommendations from the guidelines working group. MMWR 2001;50(No. RR-13).
SUID Case Registry cycle

- Identify SUID cases
- Collect data
- Review records
- Analyze results
- Act on findings
- Evaluate and refine

The cycle continues in a loop, moving from one step to the next.
Why do we need a registry?

• To accurately monitor the incidence of and characteristics associated with deaths attributed to SUID in the United States
• Use data to inform prevention activities and potentially save lives
How is death certificate data limited?

- Only describe infant demographics and cause of death
- Don’t mention the quality of the death scene investigation or if one was even done
- Don’t tell about the circumstances or factors that may have contributed to the SUID death
List of terms that will be coded as a SIDS death when reported on the death certificate

- Sudden Death in Infancy or SDII
- Sudden Infant Death or SID
- Sudden Infant Death Syndrome or SIDS
- Sudden Unexplained Death or SUD
- Sudden Unexplained (Unexpected) Death in Infancy or SUDI
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- Probably SIDS
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Objectives of SUID Case Registry

1. Collect consistent information about the circumstances and events associated with SUID cases
2. Improve the quality and completeness of SUID data collection systems
3. Use sub-classifications of SUID to better understand gaps in SUID medicolegal systems
4. Improve knowledge about trends and characteristics associated with SUID
SUID review and case registry

• Process:
  – Establish a multidisciplinary review committee
  – Identify SUID cases
  – Collect data (review records)
  – Present data to the multidisciplinary review committee
  – Draw conclusions for research and prevention purposes
  – Enter data into SUID registry database
  – Act on the findings (policy, advocacy, prevention)
SUID Case Registry expected impacts

• Short Term Impact
  – Improve knowledge of events & characteristics surrounding SUID at national, state and local levels

• Medium Term Impact
  – Identify of at-risk groups
  – Develop and evaluate of prevention and education programs
  – Promote policy and practice changes for the investigation of SUID

• Long Term Impact
  – Reduce in potentially preventable infant deaths
Partners
## Non-Federal Partners

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<th>Professional medical associations</th>
<th>SIDS organizations and advocacy groups</th>
<th>Law enforcement agencies</th>
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<tr>
<td>National Association of Medical Examiners</td>
<td>National Center for Child Death Review</td>
<td>National Sheriff’s Association</td>
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<tr>
<td>American Board of Medicolegal Death Investigators</td>
<td>Association of SIDS and Infant Mortality Programs</td>
<td>International Association of Chiefs of Police</td>
</tr>
<tr>
<td>American Academy of Pediatrics</td>
<td>Cribs for Kids</td>
<td>National District Attorneys Association</td>
</tr>
<tr>
<td>International Association of Coroners and Medical Examiners</td>
<td>First Candle</td>
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<tr>
<td>International Association of Forensic Nurses</td>
<td>CJ Foundation for SIDS</td>
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Federal Partners

- Health Resources and Services Administration
- Federal Bureau of Investigation
- National Institute of Justice
- Consumer Product Safety Commission
- Indian Health Service
- Department of Defense
- National Institutes of Health
- National Center for Health Statistics
- Office of Minority Health, DHHS
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770-488-6250

http://www.cdc.gov/SIDS.htm

Disclaimer: The findings and conclusions in this presentation have not been formally disseminated by the Centers for Disease Control and Prevention/the Agency for Toxic Substances and Disease Registry and should not be construed to represent any agency determination or policy.
Thank you
Extras
Infant mortality rates due to ASSB
United States, 1990-2005

Deaths per 100,000 livebirths

Year

Source: CDC WONDER, Mortality Files
Mechanism attributed to suffocation, U.S., 2003-2004

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<tr>
<th>Mechanism</th>
<th>Percent</th>
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<tr>
<td>Unknown</td>
<td>35.2</td>
</tr>
<tr>
<td>Overlay</td>
<td>33.8</td>
</tr>
<tr>
<td>Wedging</td>
<td>14.2</td>
</tr>
<tr>
<td>Soft bedding</td>
<td>13.7</td>
</tr>
<tr>
<td>Face down on surface</td>
<td>2.6</td>
</tr>
<tr>
<td>Other</td>
<td>0.4</td>
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Sleep surface or place where death occurred, U.S., 2003-2004

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<tr>
<th>Sleep surface or place where death occurred</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Unknown</td>
<td>54.6</td>
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<tr>
<td>Bed</td>
<td>27.5</td>
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<tr>
<td>Sofa</td>
<td>10.0</td>
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<tr>
<td>Crib</td>
<td>6.8</td>
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<tr>
<td>Other</td>
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Bedsharing or co-sleeping reported, U.S., 2003-2004