SIDS and other Sleep-Related Infant Deaths

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Presentation outline

- Define SIDS, SUID, sleep-related infant death
- SIDS and other sleep-related infant death risk factors
- Show trends in SIDS and other SUID
- AAP Safe Sleep recommendations
- Data to action: Developing prevention and risk reduction strategies
  - State and federal programs and resources
  - Tailoring resources for Kentucky’s needs
What is the cause of death?

SIDS? Suffocation? Undetermined?

• 2 month old male infant
• Born at 34 completed weeks gestation
• Found unresponsive, prone on pillow in an adult bed
• Sharing a sleep surface with mom and dad
DEFINITIONS
**SUID Definition**

- **SUID**: Sudden, unexpected infant death
- **Infant deaths that:**
  - Occur suddenly and without warning
  - Have no obvious cause of death prior to investigation (unexplained)
  - May be explained following a complete investigation
  - Excludes deaths with an obvious cause such as motor vehicle accidents
- **Types of SUID**
  - SIDS
  - Accidental suffocation in bed
**SUID Types and Categories**

<table>
<thead>
<tr>
<th>Explained</th>
<th>Unexplained*</th>
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<tbody>
<tr>
<td>Long QT</td>
<td>SIDS</td>
</tr>
<tr>
<td>MCAD</td>
<td>Undetermined cause</td>
</tr>
<tr>
<td>Head injury</td>
<td></td>
</tr>
<tr>
<td>Infanticide</td>
<td></td>
</tr>
<tr>
<td>Hyperthermia</td>
<td></td>
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<tr>
<td>Infection</td>
<td></td>
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<td>Overdose</td>
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*Cause of death was unexplained by autopsy or autopsy was not completed.*
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.”

Mechanisms of Accidental Suffocation and Strangulation in Bed (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, etc
- Strangulation (infant’s head and neck caught between crib railings)

*All could be designated as ICD 10 code W75
Triple Risk Theory and SIDS

- Prone/Side sleep position
- Smoke exposure
- Soft bedding
- Bedsharing
- Overbundling or overheating
- Bedsharing plus smoking and/or alcohol

Critical Development Period
- First 6 months, highest risk at 2-4 months
- Most rapid growth
- Transition from intrauterine environment
- Most vulnerable

Vulnerable Infant
- Brainstem dysfunction
- Arousal defect
- Gene polymorphism

Exogenous stressor

Source: Filiano JJ, Kinney HC. Biology of the Neonate, 1994
## Established risk factors

**Modifiable**
- Prone/side sleep position
- Soft sleep surface
- Maternal smoking during pregnancy
- Environmental tobacco smoke
- Bed sharing
- Overheating
- Late or no prenatal care

**Protective factors**
- Breastfeeding
- Pacifier use

**Non-modifiable**
- Young maternal age
- Prematurity and/or LBW
- Male sex
- African American
- Native American
**Sleep-related deaths**

- **Sudden and unexpected infant death (SUID)**
  - Sudden and unexpected death in infancy (SUDI)

- **Most occur during sleep**
  - Suffocation, strangulation, entrapment
  - SIDS
  - Undetermined or unspecified causes
SIDS or Suffocation: Does it matter?

- SIDS
- Accidental Suffocation
- Safe Sleep
Death Certificates Surveillance

TRENDS IN SIDS AND SUID
Epidemiology of SUID

- About 4200 per year, half are SIDS
- Most frequently reported causes:
  - SIDS
    - Leading cause of postneonatal mortality
  - Unknown or undetermined cause (UNK)
  - Accidental suffocation & strangulation in bed (ASSB)
    - Leading cause of infant injury mortality
    - Potentially preventable
- American Indian and non-Hispanic black infants disproportionately affected
- Peaks 1-3 months, rare after 8 months

### Cause of Death Section from US Death Certificate

#### 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.

**IMMEDIATE CAUSE (Final disease or condition → resulting in death)**
- a. 
  - 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. 
  - Due to (or as a consequence of):

33. WAS AN AUTOPSY PERFORMED?  

- Yes  
- No

34. WERE AUTOPSY FINDINGS AVAILABLE TO COMPLETE THE CAUSE OF DEATH?  

- Yes  
- No

#### To Be Completed by MEDICAL CERTIFIER

35. DID TOBACCO USE CONTRIBUTE TO DEATH?  

- Yes  
- Probably  
- No  
- Unknown

36. IF FEMALE:  

- Not pregnant within past year
- Pregnant at time of death
- Not pregnant, but pregnant within 42 days of death
- Not pregnant, but pregnant 43 days to 1 year before death
- Unknown if pregnant within the past year

37. MANNER OF DEATH  

- Natural  
- Homicide  
- Accident  
- Pending Investigation  
- Suicide  
- Could not be determined

38. DATE OF INJURY (Mo/Da/Year) (Spell Month)

39. TIME OF INJURY

40. PLACE OF INJURY (e.g., Decedent’s home; construction site; restaurant; wooded area)

41. INJURY AT WORK?  

- Yes  
- No

42. LOCATION OF INJURY:

- State:  
- City or Town:  
- Street & Number:  
- Apartment No.:  
- Zip Code:

43. DESCRIBE HOW INJURY OCCURRED:

44. IF TRANSPORTATION INJURY, SPECIFY:  

- Driver/Operator  
- Passenger  
- Pedestrian  
- Other (Specify)
Terms coded as SIDS (R95) when reported on the death certificate

- Crib or Cot Death
- Sudden Infant Death
- Sudden Infant Death Syndrome or SIDS
- 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)
- Presumed SIDS/Probably SIDS/ Consistent with SIDS
# Cause of Death ICD codes

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<tr>
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<tbody>
<tr>
<td>SIDS</td>
<td>798.0</td>
<td>R95</td>
</tr>
<tr>
<td>Unknown cause</td>
<td>799.9</td>
<td>R99</td>
</tr>
<tr>
<td>Accidental suffocation and strangulation in bed; Accidental mechanical suffocation in bed or cradle</td>
<td>E913.0</td>
<td>W75</td>
</tr>
<tr>
<td>Unspecified threat to breathing; Accidental mechanical suffocation by unspecified means</td>
<td>E913.9</td>
<td>W84</td>
</tr>
</tbody>
</table>

ICD: International Statistical Classification of Diseases and Related Health Problems
CDC Research

• Decline in SIDS from 1999-2001 was offset by increasing rates of:
  – Cause unknown/unspecified
  – Other SUID (suffocation, wedging, overlaying, poisoning)

Infant Mortality Rates due to SIDS, SUID* & Unknown/Unspecified Causes

* SUID include accidental suffocation and strangulation in bed; other accidental suffocation and strangulation; and neglect, abandonment and other maltreatment syndromes.
Infant Mortality Rates due to SIDS, SUID* & Unknown/Unspecified Causes

* SUID include accidental suffocation and strangulation in bed; other accidental suffocation and strangulation; and neglect, abandonment and other maltreatment syndromes.
US SUID-specific infant mortality rates 1990-2010

Deaths per 100,000 births

Combined  SIDS  Unknown  ASSB


SIDS: sudden infant death syndrome, UNK: Unknown cause, ASSB: accidental suffocation and strangulation in bed,
Combined SUID: SIDS+UNK+ASSB
Source: CDC WONDER, Mortality Files
Proportion of SUID Unexplained by Autopsy, or no Autopsy

SIDS: Sudden infant death syndrome
UNK: Unknown cause
ASSB: Accidental suffocation and strangulation in bed

1996
- SIDS: 84%
- UNK: 14%
- ASSB: 2%

2006
- SIDS: 58%
- UNK: 27%
- ASSB: 15%
Why the change in trends in SIDS and other SUID since 1999?

- Way medical examiners and coroners certify these deaths seems to be changing
  - Moving away from SIDS as a diagnosis
  - Reporting more deaths as unknown or as suffocation

- Reason unknown, but possibly related to...
  - More thorough investigations
  - Stricter adherence to 1991 SIDS definition
  - Increased influence of child death reviews

Infant Supine Sleep Position
1992 - 2010

Source: National Infant Sleep Position Study
Kentucky data
SIDS mortality rates

Source: National Center for Health Statistics, CDC
SUID (R95, R99, W75) mortality rates

Source: CDC WONDER, Mortality Files
SUID (R95, R99, W75, W84) mortality

Source: CDC WONDER, Mortality Files
Postneonatal mortality

Deaths per 100,000 births

Source: CDC WONDER, Mortality Files
SUID Mortality by Race, Kentucky (per 100,000 live births)

<table>
<thead>
<tr>
<th>Year</th>
<th>Black</th>
<th>White</th>
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<tbody>
<tr>
<td>1989-1990</td>
<td>294.0</td>
<td>165.3</td>
</tr>
<tr>
<td>1999-2000</td>
<td>179.2</td>
<td>136.0</td>
</tr>
<tr>
<td>2009-2010</td>
<td>280.1</td>
<td>166.3</td>
</tr>
</tbody>
</table>

Abbreviations: SUID: includes sudden unexpected infant deaths coded as R95, R99, W75, W84
Source: CDC WONDER, Mortality Files
Prevalence of supine sleep positioning according to maternal race and ethnic origin, 1992–2010.
Prevention and Risk Reduction

DATA TO ACTION
AAP Safe Sleep Recommendations, 2011

- Purpose: to reduce the risk of SIDS and sleep-related suffocation, asphyxia, and entrapment

- Policy and Technical report
  - Policy statement: Summary of recommendations
  - Technical Report: background literature review and data analyses

- Should be used consistently until 1 year of age
  - Most epidemiological studies upon which these recommendations are based include infants up to 1 year of age
AAP Safe Sleep Recommendations, 2011

- Back to sleep for every sleep
- Use a firm sleep surface
- Room-sharing without bed-sharing is recommended
- Keep soft objects and loose bedding out of the crib
- Consider offering a pacifier at nap time and bedtime
New AAP recommendations

- **Breastfeeding**
  - Breastfeeding is associated with a reduced risk of SIDS.

- **Immunizations**
  - Evidence suggests that immunization reduces the risk of SIDS by 50 percent
  - Immunize infants per AAP and CDC recommendations

- **No bumper pads**
  - No evidence that bumper pads prevent injuries
  - Potential risk of suffocation, strangulation or entrapment.
Other AAP Risk Reduction Recommendations

- Avoid smoke exposure
- Avoid alcohol and illicit drug use
- Get regular prenatal care
- Avoid overheating
- Supervised, awake tummy time
- Avoid commercial devices marketed to reduce the risk of SIDS
- Do not use home cardiorespiratory monitors as a strategy for reducing the risk of SIDS
Community-level AAP Recommendations

- Model safe sleep in hospital
- Target education to health care professionals, staff in newborn nurseries and NICUs, and child care providers
- Encourage media and manufacturers of infant sleep products to follow safe-sleep guidelines in their messaging and advertising
- Expand the national campaign to reduce SIDS risks
  - Focus on safe sleep environment
  - Include all sleep-related infant deaths: SIDS, suffocation, and other accidental deaths.
  - Pediatricians, family physicians, and other primary care providers should actively participate in this campaign.
Don’t reinvent the wheel

DEVELOPING PREVENTION STRATEGIES
Curricula available by target group

- **Pharmacists, first responders, child care workers, nurses, parents, caregivers**
  - [http://www.sidscenter.org/trainingtoolkit.html](http://www.sidscenter.org/trainingtoolkit.html)
  - [http://www.sidscenter.org/SafeSleep/index.html](http://www.sidscenter.org/SafeSleep/index.html)

- **Comprehensive family education trainer tips**
  - Texas training titled: Safe Sleep for Babies: A Community Training
  - [Safe Sleep for Babies: A Community Training - DFPS](http://www.dfps.state.tx.us/Room_to.../Safe_Sleep_Training-English.pdf)

- **Hospital Safe Sleep Program**
  - Mike Goodstein’s program on Starting A Hospital-Based Infant Safe Sleep Program
Safe Sleep Campaign Example: ABC Every time

- Alone, Back, Crib; Every time, no exceptions
- Free media flyers and sound bytes for radio
- From: B’More for Healthy Babies, Baltimore MD

http://www.healthybabiesbaltimore.com/ourinitiatives/safe-sleep

“Too many Baltimore babies die because they aren’t sleeping safe.”

LaQuan Williams
Wide Receiver, Baltimore Ravens
North Carolina Infant Safe Sleep Program

- **HOPES**
  - Program to award hospitals with outstanding Safe Sleep practices

- **Baby's Easy Safe Sleep Training (BESST)**
  - 2-hour workshop to train health and human services professionals how to promote infant safe sleep to families and caregivers

http://www.nchealthystart.org/backtosleep/index.htm#one
Texas Safe Sleep Education and Outreach

- **Safe Sleep For Babies**
  - Safe Sleep Checklist: to check their baby’s sleep environment for safety. Providers can give to new and expecting parents or keep copies in their waiting room.
  - Safe Sleep for Babies Fact Sheet

- **Safe Sleep for Babies: A Community Training**
  - Training manual for talking with parents, grandparents and caregivers about the best practices for safe infant sleep.
  - Frequently asked questions, tips about presenting information to parents and caregivers and parent handouts.
  - Topics: myths and facts about safe sleep, crib safety and how to talk with grandparents, day cares and babysitters about safe sleep.

- [http://www.dshs.state.tx.us/mch/#safesleep2](http://www.dshs.state.tx.us/mch/#safesleep2)
FEDERAL RESOURCES
Safe to Sleep Campaign

- Expanded from Back to Sleep September 2012
- Collaborators: HRSA, CDC, AAP, ACOG, First Candle, ASIP
- Revised education materials based on 2011 AAP recommendations
- National and tailored outreach activities
Safe to Sleep Campaign Outreach

- General
- African American
- American Indian/Alaska Native (Healthy Native Babies Project)
- Health Professionals (Nurses & Pharmacists)
- Statewide efforts (Arkansas)
Safe to Sleep Campaign Materials

Safe Sleep For Your Baby
Reduce the Risk of Sudden Infant Death Syndrome (SIDS) and Other Sleep-Related Causes of Infant Death

Ponga a su bebé a dormir sin peligro
Reduce el riesgo del síndrome de muerte súbita del bebé y de otras causas de muerte relacionadas con el sueño

Safe Sleep For Your Baby
Reduce the Risk of Sudden Infant Death Syndrome (SIDS) and Other Sleep-Related Causes of Infant Death

Safe Sleep For Your Baby
Reduce the Risk of Sudden Infant Death Syndrome (SIDS) and Other Sleep-Related Causes of Infant Death
Safe to Sleep Campaign Materials (cont’d)

Safe Sleep For Your Baby

Reduce the Risk of Sudden Infant Death Syndrome (SIDS) and Other Sleep-Related Causes of Infant Death

For more information about SIDS, contact the Safe to Sleep campaign at 1-800-339-4479 or visit www.safetosleep.org.

Safe Sleep For Your Grandbaby

Reduce the Risk of Sudden Infant Death Syndrome (SIDS) and Other Sleep-Related Causes of Infant Death

For more information about SIDS, contact the Safe to Sleep campaign at 1-800-339-4479 or visit www.safetosleep.org.
Resources

Contact the *Safe to Sleep* Campaign at:

1-800-505-CRIB (2742)

or

[http://www.nichd.nih.gov/SIDS](http://www.nichd.nih.gov/SIDS)
HRSA MCHB-Funded SUID/SIDS Resource Centers

- SUID/SIDS Project IMPACT
- SUID/SIDS Program Support Center
- SUID/SIDS Resource Center

www.sidscenter.org

SUID/SIDS Project at the National Center for Cultural Competence
Collaborative Improvement & Innovation Network (COIIN) and Safe Sleep

- **Aim**: Improve safe sleep practices by increasing the prevalence of safe sleep practices including placing infants to sleep on their backs, alone in crib, and without soft bedding.

- **Strategies**
  1. Work with non-primary infant caregivers to assure they commit to practicing and promoting safe sleep recommendations.
  2. Standardize provision of safe sleep education and training for providers.
  3. Develop strategic alliances and cooperative partnerships to endorse AAP safe sleep recommendations and promote safe sleep.
A new surveillance system to monitor trends in SIDS and other SUID

**CDC’S SUID CASE REGISTRY**
SUID Case Registry Model

- **Builds upon current Child Death Review activities and protocols**
  - Places responsibility for data collection with Child Death Review
  - Uses pre-existing variables
  - Integrates new and/or modified SUID-related variables into Case Reporting System
  - Avoids duplication of efforts

- **Strengthens states’ ability to identify, review, and enter data for all SUID cases**

- **Increases knowledge about the circumstance surrounding the death**

- **Enhances states’ capacity for data-driven prevention strategies**
Main Objectives for the SUID Case Registry

- To create state-level surveillance systems that build upon Child Death Review activities
- To categorize SUID using standard definitions
- To monitor the incidence of different types of SUID
- To describe demographic and environmental factors for each type of SUID
- To inform prevention activities and potentially save lives
Variables

- **Individual variables**
  - Sleep environment
  - Maternal health, including pregnancy complications and injury
  - Infant health, including newborn screening

- **System variables**
  - Components of death scene investigation
  - Tests and exams performed during autopsy
SUIDIRF
Law Enforcement reports
Witness interviews
Scene reenactment
Scene photos

EMS reports
Hospital reports

Medical records
Social service records

Death Certificate
ME/C report
Autopsy report

SUID case review by multidisciplinary team
All states collecting SUID variables, 2013

*Gold states are 2012 CDC-funded SUID Case Registry states - 9
*Gray states voluntarily collecting data for SUID - 9
SUID Case Registry: Moving data to action

- Moving from data collection to SUID prevention
- Identifying prevention collaborations and opportunities
  - Federal partners and national organizations
  - Safe to Sleep campaign
  - State Safe Sleep Coalitions
  - Home visiting programs
  - Smoking cessation programs
  - Breastfeeding programs
TAILORING RESOURCES FOR KENTUCKY’S NEEDS
Use your data to inform your actions

- Who is at highest risk?
- What are the barriers to providing a safe sleep environment?
- What are the beliefs and perceptions of caregivers and providers?
- When are these deaths occurring (age, place)?
- Where do deaths occur?
- Why are these deaths occurring?
Bill Gates: My Plan To Fix The World's Biggest Problems

Answer: Measure Them!

“An innovation--whether it's a new vaccine or an improved seed--can't have an impact unless it reaches the people who will benefit from it. We need innovations in measurement to find new, effective ways to deliver those tools and services to the clinics, family farms and classrooms that need them.”

Wall Street Journal Headline, January 26, 2013
Reasons for unsafe sleep practices

- **Non-supine sleep position**
  - Fear of choking/aspiration
  - Infant comfort—sleeps better/longer
  - Side often seems like a good compromise

- **Soft bedding**
  - Infant comfort (warmth and softness)
    - Some believe that blankets can be used safely if placed away from the infant’s head, if use light receiving blanket, or if use blanket with breathing holes (crocheted)
  - Pillows used as a barricade to prevent falls from a bed or sofa

Robida D, & Moon RY. Arch Dis Child. 2012
Ajao TI, Oden RP, Joyner BL, Moon RY. Pediatrics. 2011
Moon RY, Oden RP, Joyner BL, Ajao TI. J Pediatr. 2010
Partners - health department

- Injury Prevention (KY has a Core grant from CDC IP)
- Home Visiting
- Smoking cessation
- Breastfeeding
- WIC
- Immunizations
- Prenatal Care
- PRAMS
Partners - outside agencies

- **Home Visiting run by other agencies**
  - Early Head Start, Healthy Families, Nurse Family Partnership, CPS

- **Child care and child development agencies**
  - Head Start and certifying agencies
  - Early Intervention

- **Pediatricians, OB/GYNs and Midwives**

- **Smoking cessation**
  - American Legacy and American Lung Association

- **Breastfeeding**
  - La Leche League, Hospital lactation consultants

- **Childbirth educators**
Contact information:

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Centers for Disease Control and Prevention

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For more information please contact Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333
Telephone, 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-6348
E-mail: cdcinfo@cdc.gov  Web: www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.