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Project IMPACT, SUID Webinar
March 2009

**Sudden Unexpected Infant Death (SUID):
National Developments, Studies and
Opportunities**

March 30, 2009

Moderator:
Mary Adkins

The National SUID/Child Death and
Pregnancy Loss Program

**Sudden Unexpected Infant Death (SUID):
National Developments, Studies and
Opportunities**

Project IMPACT Webinar
March 30, 2009
2:00 - 3:30 p.m. Eastern Time

The National SUID/Child Death
and Pregnancy Loss Program

Paul Rusinko, Director
National SUID/Child Death and Pregnancy Loss Program
Maternal and Child Health Bureau
Department of Health and Human Services

Mary Adkins, RN, MSW, Moderator
Project Director
National SUID/Child Death and Pregnancy Loss
Program/Project IMPACT

The National SUID/Child Death and
Pregnancy Loss Program

Overview of Webinar

- Describe the National SUID/Child Death and Pregnancy Loss Program and four Program Centers
- Examine the transition in SIDS and SUID
- Present the February 2009 *Pediatrics* article: [Infant Accidental Suffocation and Strangulation in Bed](#)
- Describe the CDC SUID Initiative and Case Registry Pilot

The National SUID/Child Death and Pregnancy Loss Program

Presenters:

Paul Rusinko, Director
National SUID/Child Death and Pregnancy Loss Program

Mary Adkins, RN, MSW, Project Director
Project IMPACT

Sandra J. Frank, JD, President
Association of SIDS and Infant Mortality Programs

Carrie Shapiro-Mendoza, PhD, MPH, Team Leader and Epidemiologist
CDC SUID Initiative

Lena Teresa Camperlengo, RN, MSN, Program Coordinator
CDC SUID Initiative

The National SUID/Child Death and Pregnancy Loss Program

Four National SUID/Child Death and Pregnancy Loss Centers funded by the federal Maternal and Child Health Bureau

1) Project IMPACT at ASIP
The communication hub – convening, connecting and providing technical support to state and local efforts.

2) Resource Center at Georgetown University
A gateway to critical information on risk reduction, prevention, and bereavement for pregnancy loss, stillbirth, and sudden unexpected infant and child death.

The National SUID/Child Death and Pregnancy Loss Program

Four National SUID/Child Death and Pregnancy Loss Centers funded by the federal Maternal and Child Health Bureau

3) Program Support Center at First Candle
Provides education, training, and bereavement services, including a 24-hour bilingual bereavement counseling helpline.

4) National Center for Cultural Competence at Georgetown Univ.
Provides technical assistance and resources on culturally and linguistic competence to help programs effectively address racial and ethnic disparities in perinatal, infant and child mortality and pregnancy loss.

The National SUID/Child Death and Pregnancy Loss Program

CONTACT INFORMATION

Program Support Center

First Candle

1314 Bedford Avenue, Suite 210

Baltimore, MD 21208

(800) 638-7437

http://firstcandle.org/health/health_human.html

The National SUID/Child Death and Pregnancy Loss Program

CONTACT INFORMATION

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U.S. Trends in SIDS and SUID-related Mortality

Carrie K. Shapiro-Mendoza PhD, MPH

March 30, 2009
Project IMPACT Webinar

Division of Reproductive Health
National Center for Chronic Disease Prevention and Health Promotion
Centers for Disease Control and Prevention



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Presentation outline

- Define SIDS and SUID
- Discuss trends in SIDS and SUID
- Present Pediatrics article from Feb 2009 regarding increasing rates of ASSB mortality

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



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.”

* Willinger M, James LS, Catz C. *Pediatr Pathol* 1991.

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

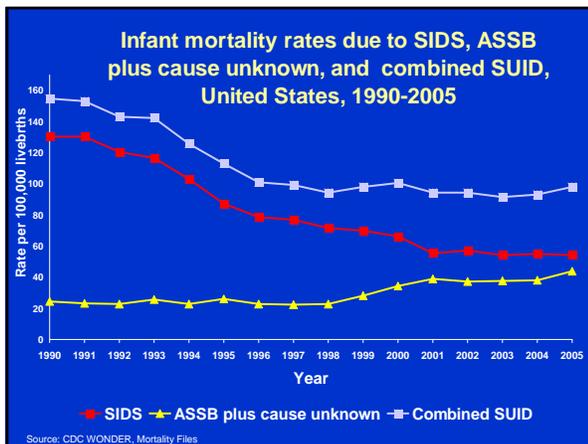
Why be concerned about SUID?

- 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

CDC Research

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

* Shapiro-Mendoza CK, Tomashek KM, et. al., Am J Epidemiol, 2006.



Change in Practices?

- This change in classification may be explained by changes in practice:
 - How death scene investigations are conducted
 - How cause of death diagnoses are made
- Comprehensive death scene investigation is critical to accurately classify ASSB
- Autopsy findings alone often cannot differentiate between ASSB and SIDS

* Shapiro-Mendoza CK, Tomashek KM, et. al., Am J Epidemiol, 2006.

ARTICLE

US Infant Mortality Trends Attributable to Accidental Suffocation and Strangulation in Bed From 1984 Through 2004: Are Rates Increasing?

Carrie K. Shapiro-Mendoza, PhD, MPH¹; Melissa Kimball, MPH¹; Kay M. Tomashek, MD, MPH²; Robert N. Anderson, PhD³; Sarah Blanding, MPH¹

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The authors have indicated they have no financial interests relevant to this article to disclose.

PEDIATRICS Volume 123, Number 2, February 2009

Why did we conduct this study?

- Anecdotal data said:
 - Many medical examiners and coroners were no longer reporting SIDS as a cause of death
 - Accidental suffocation in a sleep environment preferred as a diagnosis in place of SIDS

Objectives

- Objectives**
1. To explore trends in ASSB from 1990 through 2004
 2. To compare trends in other SUID (SIDS and unknown cause) with ASSB
 3. To evaluate demographic characteristics of infants who reportedly died of ASSB
 4. To describe the primary mechanisms reported as leading to these ASSB deaths

- Study Methods**
- Population-based, descriptive study
 - U.S. mortality data from the Compressed Mortality File, 1990-2004
 - CDC WONDER (<http://wonder.cdc.gov>)
 - Secondary analysis of all ASSB-coded deaths:
 - Used 2003 and 2004 mortality files with written text in the cause-of-death section of the death certificate

Definition of underlying cause of death

Underlying cause of death category	ICD 9 Codes (1990-1998)	ICD 10 Codes (1999-2004)
ASSB	E913.0	W75
SIDS	798.0	R95
Unknown cause	799.9	R99

ICD: International Statistical Classification of Diseases and Related Health Problems

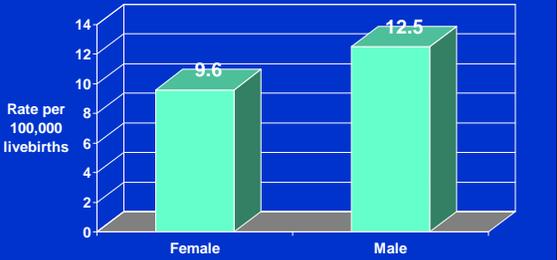
Examples of ASSB

- 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)

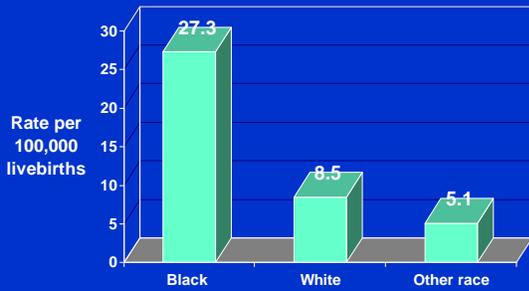


Results

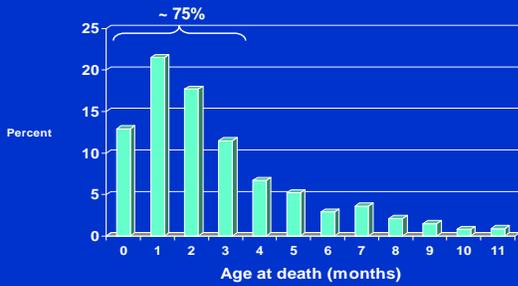
Infant mortality due to ASSB by gender, U.S., 2002-2004



Infant mortality due to ASSB by race, U.S., 2002-2004

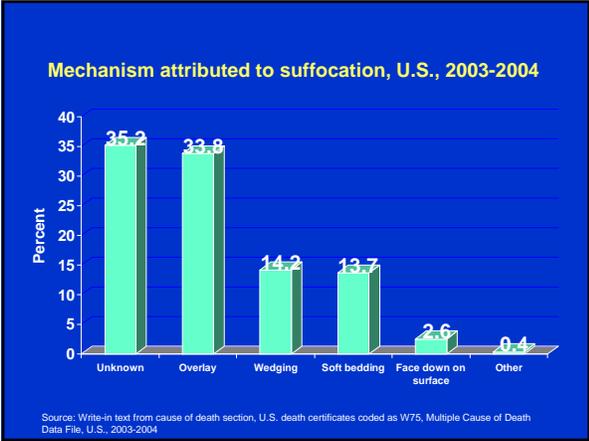


Percent distribution of age at death for ASSB, United States, 2002-2004



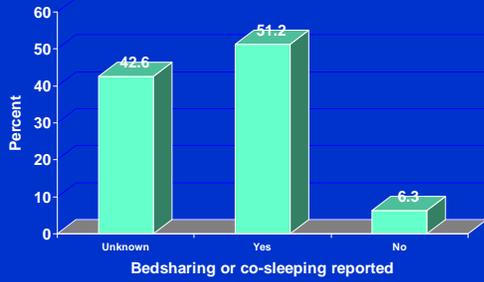
Source: Multiple Cause of Death Data file for the U.S., 2002-2004

Secondary analysis





Bedsharing or co-sleeping reported, U.S., 2003-2004



Source: Write-in text from cause of death section, U.S. death certificates coded as W75, Multiple Cause of Death Data File, U.S., 2003-2004

Summary

Summary

- Infant mortality rates attributable to ASSB have quadrupled since 1990
 - Most dramatic increase occurring since 1997
 - Reason for the increase is unknown
- Male, black infants are disproportionately affected
- Infants can die in all sleep environments
 - Adult bed, crib, other sleep surfaces
- Potentially preventable

Why the increase in ASSB?

- Way medical examiners and coroners certify 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

What is needed?

- Improved data to increase knowledge about events and circumstances associated with ASSB and other SUID
- A SUID Case Registry that builds upon child death review may be the answer

CDC SUID Initiative Team

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

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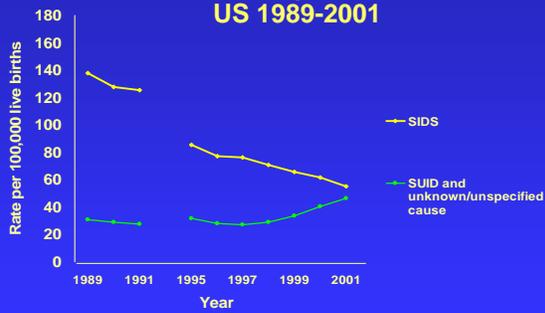
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Thank you

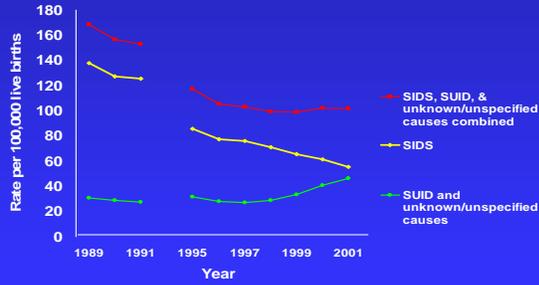
Extras

Infant Mortality Rates due to SIDS, SUID* & Unknown/Unspecified Causes US 1989-2001



* 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 US 1989-2001



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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

CDC's SUID Initiative and SUID Case Registry

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Lena Camperlengo RN, MPH, DrPH student

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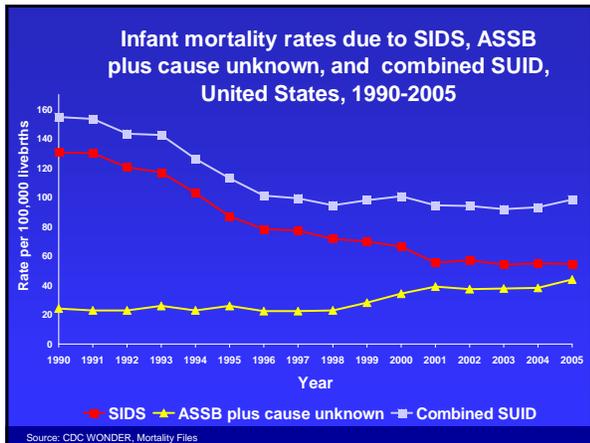
Presentation outline

- Background
- CDC's SUID Initiative Activities
 - SUID Reporting Form
 - SUID Training Academies
 - SUID Case Registry Feasibility Study
- Development of the SUID Case Registry

Background

Why be Concerned with SUID?

- SUID: about 4600 per year
 - Rates comparable to birth defects mortality
 - About 2500 of these are SIDS
- SIDS
 - Leading cause of post-neonatal mortality
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- ### Why be concerned about changes in reporting practices?
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- ### 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

CDC's SUID Initiative 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

Completed SUID Initiative Activities

- Revised the 1996 infant death scene investigation form (SUIDI Reporting Form)
- Developed SUIDI training curriculum and materials
- Conducted 5 regional SUIDI Training Academies
- Disseminated and promoted the use of the SUIDI Reporting Form, training curriculum and materials
 - Now available to download for free: www.cdc.gov/sids

Impact of Completed SUID Initiative Activities

- Obtained professional endorsements
 - National Sherriff's Association
 - National Association of Medical Examiners
- Trained 250 plus medico-legal professionals and child fatality advocates as trainers
 - These trainers trained an additional 15,000 +
- Integrated training materials into academic curricula
- Educated partners who facilitated state and local legislation
- Encouraged implementation of jurisdictional death scene investigation policies and practices

Completed SUID Initiative Activities

SUID Case Registry feasibility study

- Partnered with 7 states and their teams who were participating in NVDRS
- Asked states to retrospectively collect data from all SUID cases from 2004-2005
- Abstracted data from a variety of sources
- Assessed the completeness of data available to complete CDC's newly revised SUIDI Reporting form
- Provided information to begin the development of a SUID Case Registry

Recommendations

- Build upon Child Death Review system
 - Good access to data
- Minimize the number of variables collected
- Expand the case definition
- Develop a web-based data collection system
- Improve distribution of and training related to investigation of SUID, including SUIDI Reporting Form

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 Pilot Evaluation Report, 2007

Current SUID Initiative Activities

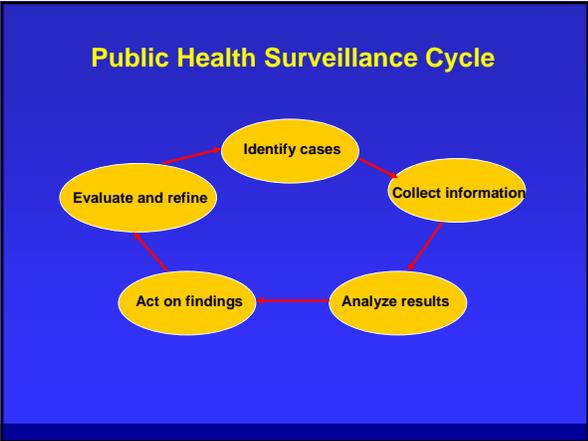
- Evaluating the success and impact of the SUIDI Training Academies
 - More than 250 trained as trainers
 - More than 15,000 others trained
 - Did jurisdictional or state policies change?
- Developing a National SUID Case Registry
 - Information Gathering Sessions
 - Identify variables needed
 - Funding announcement

Developing a National SUID Case Registry

What is a case registry?

- A surveillance tool
- Surveillance: Routine collection, analysis, interpretation, and dissemination of data about a health-related event
- Objective: to reduce morbidity and mortality and to improve health in the community

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



Current SUID Surveillance: U.S. Mortality Files

Death certificates:

- Effectively describes infant demographics and cause of death, but ...
- Does not record death scene investigation or autopsy quality
- Lacks information about the circumstances or factors that may have contributed to SUID mortality

Why do we need a registry?

- To accurately monitor the incidence of and characteristics associated with deaths attributed to SUID in the United States
- To supplement data we have from death certificates
- To use data to inform prevention activities and potentially save lives
- To provide a potential source of cases for case-control studies

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

Activities of SUID Case Registry

- Created Program Models
 - Logic Model, Concept Model & Data Flow Model
 - Enhancement of National Child Death Review system
- Defined minimum variable set and anticipated research and program evaluation questions
- Developed standard sub-categories of SUID to better understand and improve SUID medico-legal practices and systems
- Planned pilot data collection activities for a SUID case registry in 4 - 7 states

SUID Case Registry Pilot Project Funding Announcement

- Released March 11, 2009
- All state health departments demonstrating access to required data sources are eligible
- Proposals must be submitted electronically by May 11, 2009
- The announcement (CDC-RFA-DP09-904) may be accessed on www.grants.gov

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



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

Non-Federal Partners

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

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Questions & Answers

The National SUID/Child Death and Pregnancy Loss Program

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