

Healthy Babies are Dying!

**Understanding and Preventing
 Sleep-Environment-Related Deaths in Infancy**

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 Scott Krugman, MD, MS
 Stephanie S. Regenold, MD, MPH

April 15, 2009

Session Overview

- ❑ Part 1:
 The role of unsafe sleep in infant mortality
 ➤ Dr. Stephanie Regenold
- ❑ Part 2:
 Understanding sleep-environment-related infant deaths
 ➤ Dr. Carolyn Fowler
- ❑ Part 3:
 Preventing sleep-environment-related deaths
 ➤ Dr. Scott Krugman
- ❑ Discussion (Q&A)
 ➤ Please e-mail us your questions/comments

**Part 1:
 The Role of Unsafe Sleep in Infant Mortality**

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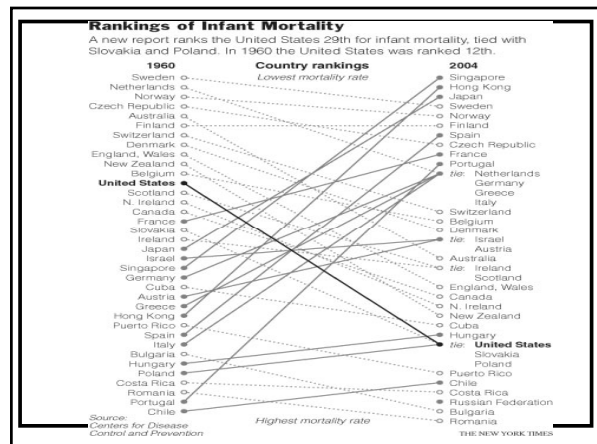
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**Infant Mortality Rate
 (IMR)**

- ❑ # of deaths among infants/1,000 live births in a year
- ❑ Infant=birth until first birthday
- ❑ Easy to compute and compare

Why look at Infant Mortality?

- ❑ Indicator of health of present and future populations
- ❑ Indicator of health disparities among different populations
- ❑ Indicator of overall health/ quality of life in a community



Infant Mortality Rate: US

- ❑ Overall 6.78 in 2004
- ❑ 6.84 in 2003
- ❑ Range: 4.67 (Asian & Pacific Islanders)--
13.6 (Non-Hispanic Blacks)

Infant Mortality in the US: Leading Causes

1. Congenital malformations
2. Low birth weight
3. SIDS

Together account for 45% of all infant deaths

Postneonatal Infant Mortality

Death of an infant from 28 days
to 1 year of age

SIDS/ Sleep-related Deaths

Leading cause of
postneonatal mortality in
the US

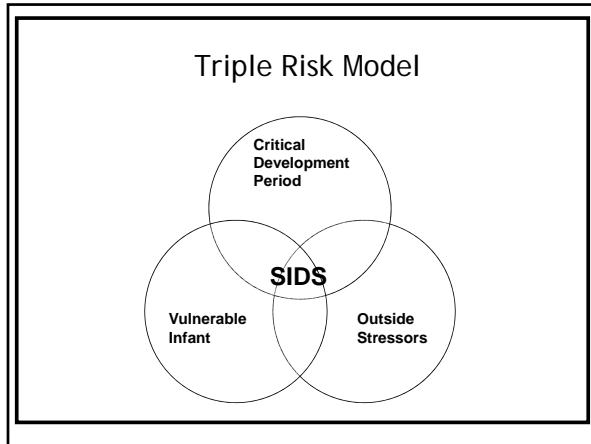
What is SIDS?

Sudden Infant Death Syndrome (SIDS) is the sudden death of an infant younger than 1 year of age that remains unexplained **after a thorough case investigation***

We'll return to this in Part 2

The Triple Risk Model

- ❑ requires the convergence of three elements that may lead to the death of an infant from SIDS:
 - Critical developmental period
 - Vulnerable infant
 - Outside stressor(s)
- ❑ All three elements must be present for SIDS to occur.
- ❑ Removing one or more outside stressors can reduce the risk of SIDS.



- ### Outside Stressors
- Stomach sleep position
 - Soft bedding
 - Tobacco smoke
 - Overheating
 - Infection

- ### What Public Health Agencies do to Improve Birth Outcomes and IMR
- Primary Health Care in Medical Home
 - Obstetric Care
 - Home Visiting
 - Drug and Alcohol Treatment
 - Intervention for Domestic Violence
 - Mental Health Care
 - Smoking Cessation
 - Family Planning
 - Nutrition Support
 - Breastfeeding Promotion
 - Safe Sleep Programs (more later)

Part 2: Understanding Sleep-Environment-Related Deaths in Infancy

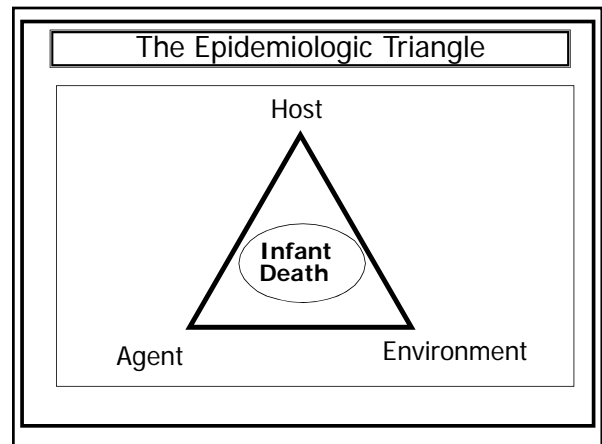
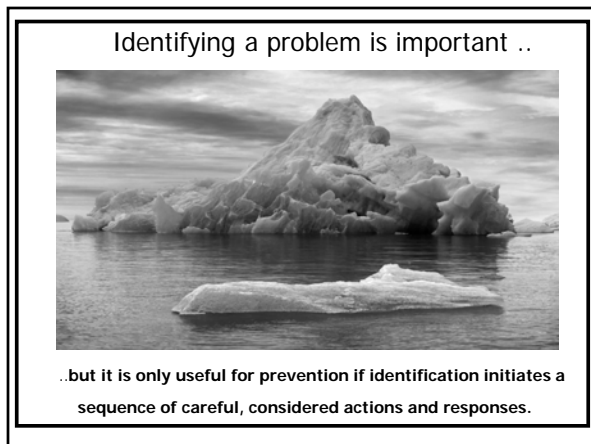
Carolyn Cumpsty Fowler, PhD, MPH

Assistant Professor, Johns Hopkins Bloomberg School of Public Health & JHU School of Nursing

Director, Injury Prevention, Baltimore County Department of Health

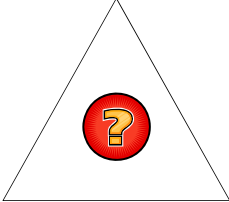
Co-Chair, Baltimore County Child Death Review Team

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Host-Agent-Environment Interactions Differ

- ❑ Infants and children interact with the environment differently from adults
 - The environment as built
 - The environment as used



Infant death prevention challenge

- ❑ Finding information about all components of the epidemiologic triangle for all causes and manners of death:
 - Host
 - Agent
 - Environment – physical and social



Investigation is Critical to Risk Reduction

Sudden Infant Death Syndrome (SIDS) is "the sudden death of an infant younger than 1 year of age that remains unexplained after a thorough case investigation."

Who investigates? Why does this matter?

What is a thorough case investigation?

Who Are the Infant Death Investigators?

The answer depends on where you are

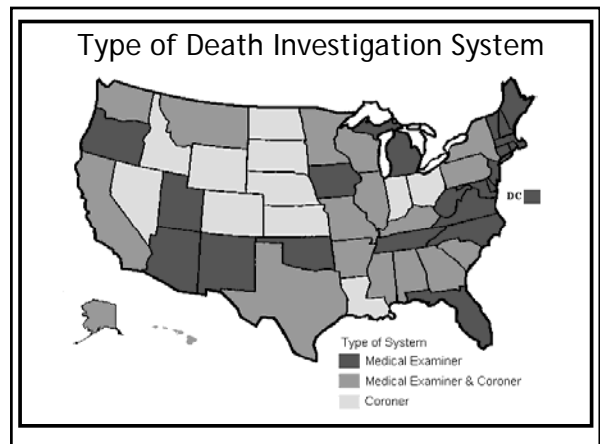
There are more than **2200** death investigation jurisdictions in the United States.

This variation in training and protocols influences the quality and consistency of the investigation and data

What's in a name?

Coroners	Medical Examiners
❑ Elected	❑ Appointed
❑ Training variable	❑ Forensic Pathologist
❑ Smaller Jurisdictions	❑ Larger Jurisdictions


There are approximately 1000 forensic pathologists in the USA (and 2200 jurisdictions – you do the math)



Know Your Death Investigators

- ❑ Do not attempt to compare data from jurisdiction to jurisdiction
- ❑ Know your Death Investigator's
 - Training
 - Experience
 - Resources
 - Protocols

CDC is currently leading efforts to achieve uniform investigation and reporting of infant deaths




Centers for Disease Control and Prevention
 Your Online Source for Credible Health Information

Sudden Infant Death Syndrome (SIDS) and Sudden Unexpected Infant Death (SUID) Initiative


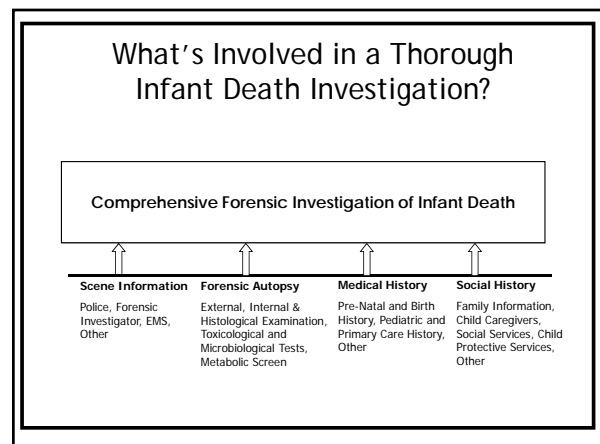
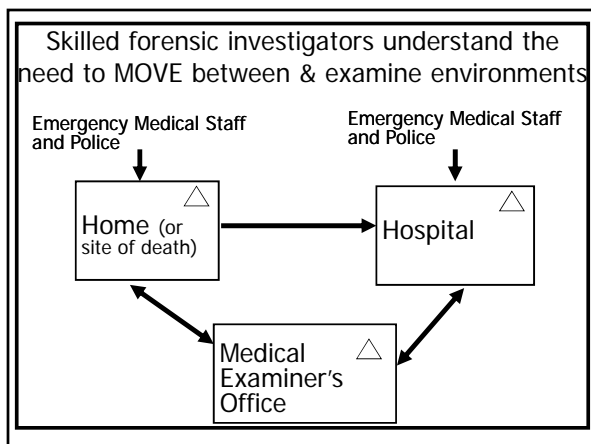
<http://www.cdc.gov/SIDS/SUID.htm>

Infant Death Investigation in MD

- ❑ All sudden, unattended or unexpected infant deaths are investigated by the Office of the Chief Medical Examiner
- ❑ We have a state-wide system. Observer differences are limited because the same team of Forensic Pathologists is investigating the deaths.



Skilled forensic investigators understand the importance of looking beyond the pathology

Investigation Findings in SIDS and SUDI

SIDS	Investigation	SUDI
Negative	Autopsy: external and internal examination	Negative
Negative	Histology, microbiology and other special tests	Negative
Negative	Toxicology (other than prescribed medications in the correct range)	Negative
Negative	Review of medical history (includes pre-natal, birth and post-natal history)	One or more of these three areas may be positive
Negative	Scene investigation	
Negative	Social history	
Natural	Manner of Death	Undetermined*

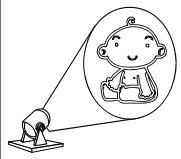
* Unfortunately, these are currently regrouped with the SIDS (natural) in Vital Statistics
 Decision criteria used at the Office of the Chief Medical Examiner, MD

Understanding "Undetermined"

- ❑ SIDS and SUDI are diagnoses of exclusion
- ❑ Investigation is complex and can be very time-consuming
 - some special test results take weeks (or months)
- ❑ Undetermined manner of death does not mean that no one bothered to investigate the death or make a decision
- ❑ Undetermined means that after extensive investigation there still was not adequate evidence to support calling the manner "natural" or "accidental" or "homicide"


Adequate review of risk factors includes both intrinsic and extrinsic risk factors:

- ❑ Intrinsic individual
 - Physical, Cognitive, Developmental
- ❑ Acquired individual
 - Physical, Behavioral
- ❑ Physical environment
- ❑ Social environment
 - Individual/family level
 - Community
 - Systems
- ❑ Injury patterns and outcomes
- ❑ Exposure
 - Does the clinical picture match the exposure?

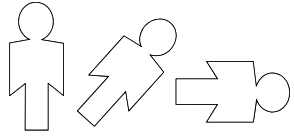


Data Finding, Integration and Response

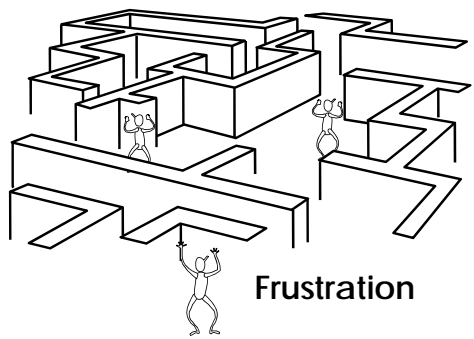
The contribution of multi-disciplinary Child Death Review Teams to the understanding and prevention of infant sleep-related deaths



PROBLEM: No single health, social service, law enforcement, or judicial system exists to track and comprehensively assess [and respond to*] the circumstances of child deaths



Dr. Michael Durfee, 1989 & JAMA 1992. [* Emphasis added]

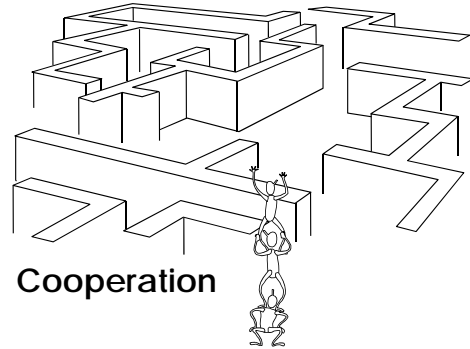


Frustration

Child Death Review

involves a systematic, multidisciplinary, and multi-agency process to coordinate and integrate data and resources from coroners (*forensic pathologists*), law enforcement, courts, child protective services, and health care providers.

Michael Durfee et al., JAMA 1992; 267: 3172



The Child Death Review Team

- ❑ Is a multidisciplinary team
- ❑ Reviews pediatric deaths
- ❑ Identifies system failures
 - Often impacting physical and social environment
- ❑ Identifies and proposes "Fixes"
 - Education
 - Legislation, regulation and public policy
 - Environmental design and engineering
- ❑ May implement risk reduction initiatives and/or advocate for implementation of strategies by others

CDRT Prevention Challenge

- ❑ Identifying intervention points for risk reduction is NOT intuitive.
- ❑ We often "see what we know"
- ❑ We may be tempted to focus exclusively on one issue or one approach (e.g., crib distribution, or public service announcements) and not consider the risk factors in our setting
- ❑ Many CDR Teams need prevention strategy training and technical support.

Valuable CDR Resources

Including a comprehensive child death review data form and national data base



NATIONAL MCH CENTER
FOR CHILD DEATH REVIEW
KEEPING KIDS ALIVE



<http://www.childdeathreview.org/>

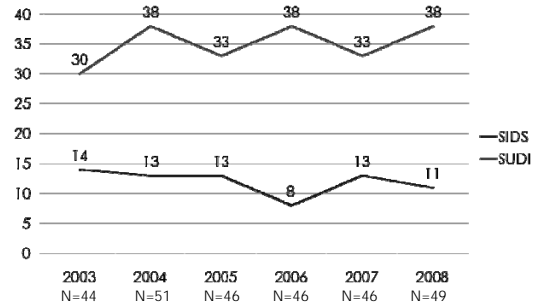
High Exposure and Poor Outcomes Makes Infant Sleep Safety a Priority Issue



Reducing the risks for infant sleep-environment-related deaths

- ❑ Despite an apparent drop in SIDS cases in Maryland, we still have a major problem. Part of the SIDS decrease is explained by changes in terminology and the introduction of SUDI (or SUID)
- ❑ SUDI cases have increased in MD
 - The majority of SUDI are due to unsafe sleep positions and are preventable
 - Risks: co-sleeping (bed-sharing), prone sleeping, couches, blanket/comforters, pillows

**SIDS and SUDI Deaths by Year
 Maryland 2003-2008 (N=282)**



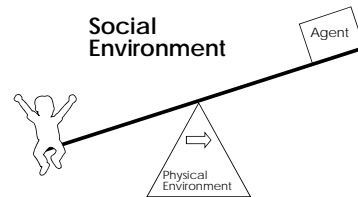
Data Source: Office of the Chief Medical Examiner, MD

“Back to Sleep” is an inadequate message



“Negative ecological balance”

Physical and social environmental factors increase the infant's risk for sleep-environment-related death.



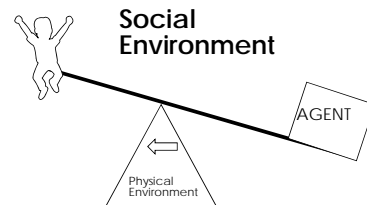
We need to change the way people look at - and respond to - risks in the infant's physical sleep environment



This will also influence the demand for, design and availability of sleep-safety-related products

We must achieve “Positive ecological balance”


Physical and social environmental factors decrease the infant's risk for sleep-environment-related death.



Social Environmental Change is Essential,
 but
 Social Norms are Against Us


“Oops she did it again”

- ❑ Who is she and what did she do?
- ❑ Brittany Spears places her infant son in a high risk situation



- ❑ The public outcry indicated public awareness of the risks to infants in cars and the need to use an infant safety seat – it provided a major prevention opportunity

What did Jennifer Lopez (& Marc Anthony) do?



- Shared pictures of their twins’ luxurious nursery
- Described co-sleeping with the twins

This did not generate a loud and immediate public outcry ... indicating limited awareness of sleep-environment risks

Parents Magazine response: “A Memo to J Lo”


Dear J. Lo:
 Parents staffers were kinda shocked at the photo of the babies’ ornate, Versailles-like nursery, which is filled with safety hazards. We want those sweet twins to stay out of harm’s way, so we’re begging you....please babyproof!

- Take the pillows, stuffed animals and blankets out of the cribs—they’re suffocation hazards.
- Get rid of the dramatic draped canopies hanging over the cribs, which can cause strangulation.
- Those cute bows tied onto the crib slats? Choking hazards as soon as the babies are big enough to get their hands on them.

http://www.goodyblog.com/playing_house/2008/03/a-memo-to-j-lo.html

The memo generated responses such as “Jennifer Lopez’s \$100k Nursery Will Kill Her Babies!”

- ❑ “Staffers at *Parents* magazine love their celebrity gossip as much as the rest of this TMZ-revering nation, so they were fawning over *People’s* \$6 million Jennifer Lopez baby photos this week, too. Except they spotted something awry with the new mom’s six-figure nursery.
- ❑ Basically, it’s a baby death trap!”



Excerpt from <http://www.jssip.com/jennifer-lopez-100k-nursery-will-kill-her-babies-20080328/>

These responses – although dramatic - did not get much attention from the media.

Challenges to Behavior Change

1. The risks of unsafe sleep environments are not widely recognized by the public, or may be discounted (“it won’t happen to me”)
2. Those contemplating may be discouraged by peers or public opinion

- ❑ **Precontemplation***
 - Unaware of problem; haven’t thought about change, or have decided not to change.
- ❑ **Contemplation***
 - Thinking about change in the near future

* These are Stages 1 & 2 of the 5-stage Transtheoretical Model (Prochaska and DiClemente, 1992)

Challenges to Behavior Change - contd.

3. Co-sleeping (or bed-sharing) is a common practice and has many outspoken advocates
- "How to" books and magazine articles
 - Numerous blogs, testimonials and photographs
 - Most "how to co-sleep safely" advice is accompanied by photographs that show unsafe practices

A web search for "co-sleeping" information and images yields extensive bad information

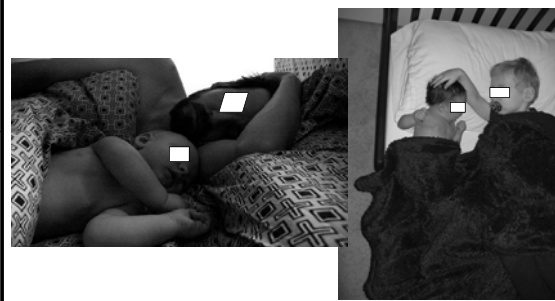
"Co-sleeping" Creative Commons (cc) images



"Co-sleeping" Creative Commons (cc) images



"Co-sleeping" Creative Commons (cc) images



Safe Sleep Education is Inexpensive and Can Be Done in Many Settings

- Public health clinics
- Home visiting programs
- Hospitals—in L&D, pediatric units and outpatient clinics, EDs, OB clinics
- Emergency services
- Churches
- Community organizations

But it's not easy – we must move "Beyond Basic Brochure Distribution"

Safe Sleep Education


- Is needed to change social norms about sleep-environment-related risks
- Needs to be addressed early and often!
- Must involve credible "key informants" or "key influencers"
- Should be institutionalized in settings such as newborn nurseries and pediatrics.
- Must address barriers to adoption and opposing messages
- Must be repeated and reinforced – at the community level

Beyond Parents: Safe Sleep Education for the Provider and Public Safety Community

- ❑ Police and EMS personnel, if educated, can provide us with essential information
 - Such as the presence and/or use of a crib; sleep position, etc
- ❑ Day care providers, baby sitters, grandparents, and others who care for infants must be included
- ❑ Physicians, nurses, child birth educators and social services providers are valuable influencers
- ❑ The child passenger safety community (can integrate infant sleep safety and installation of infant safety seats)
- ❑ The media (and many more ..)

**Changing Behavior is Challenging
 (but it is possible)**

**Knowledge + Attitudes + Beliefs + Skills + Resources
 may = Behavior Change**



One pound of learning requires ten pounds of common sense to apply it.
 Persian Proverb

**Part 3:
 Preventing Sleep-Environment-Related Deaths in Infancy**

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 Franklin Square Hospital Center

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**5 Years of Infant Deaths
 Baltimore County, 2003-2007**



**BALTIMORE COUNTY
 MARYLAND**

The Data and Our Response

**Infant Deaths* in Baltimore County
 2003-2007**

- ❑ 69 infants under 1 year
- ❑ 40% female, 60% male
- ❑ 55% white, 35% African American, 6% Hispanic
- ❑ Average age: 113 days,
 - median 85 (range between 7 days and 325 days)

* These 69 infant deaths were sudden, unexpected or unattended and, by Maryland law, fell under the jurisdiction of the Office of the Chief Medical Examiner.

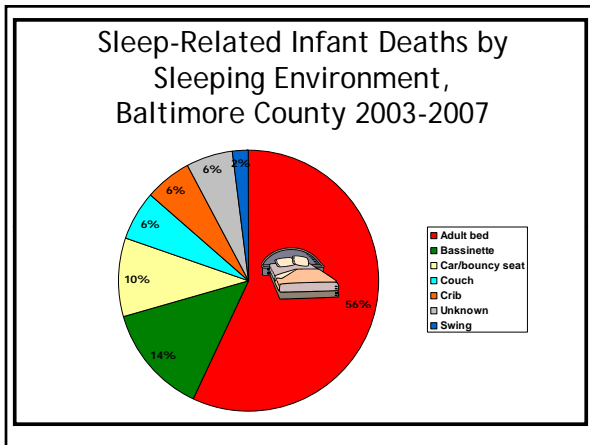
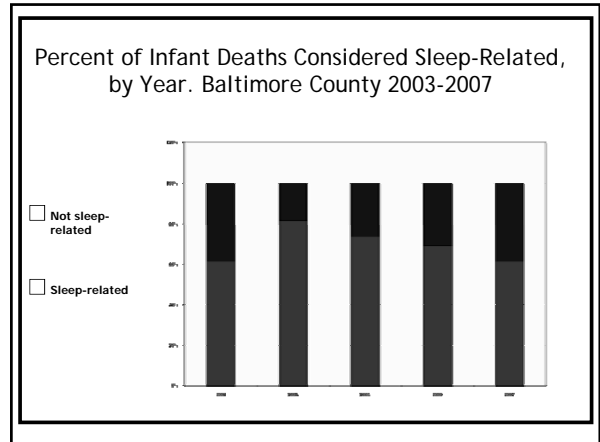
Identifying Sleep-Environment-Related Infant Deaths in Baltimore County (2003-2007)

- ❑ Cause:
 - 33 SUDI (Manner = Undetermined) 48%
 - 32 of 33 sleep-related
 - 13 SIDS (Manner = natural) 19%
 - 12 of 13 sleep-related
 - 4 asphyxia (Manner =accidental) 6%
 - 2 exclusively sleep-related
 - 1 in unsafe sleep environment
 - 1 not sleep-related

Circumstances of Infant Deaths in Baltimore County (2003-2007)

- Circumstances of death
 - 46 purely sleep-related (67%)
 - 6 in unsafe sleep environment but other factors also present (8%)
 - 5 homicides (7%)
 - 1 motor vehicle crash passenger
 - 1 aspiration of foreign body
 - 9 medical conditions
 - 1 remains unknown

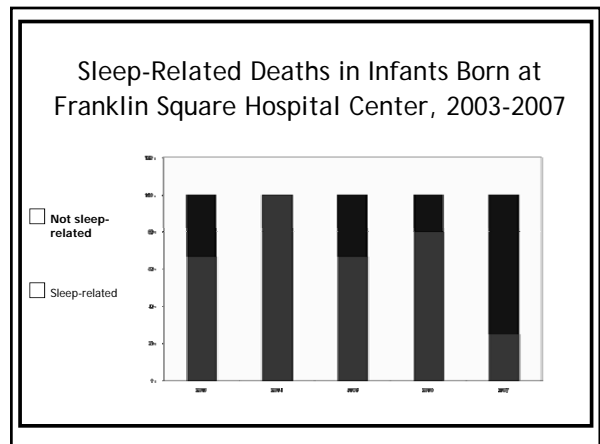
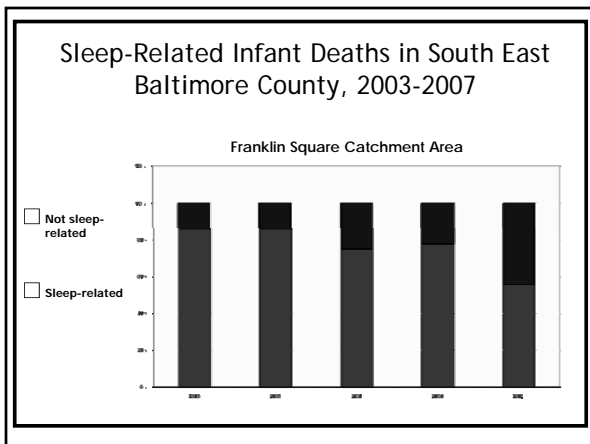
75% (52) of the 69 infants who died were in an unsafe sleep environment at the time of their death



FSHC Experience 2003-2007

Franklin Square Hospital Center
 Centered on You
 MedStar Health

- 19 of the infants who died were born at Franklin Square Hospital Center
 - 10 of these also presented to FSHC Pediatric ED
 - 9 presented to other hospitals
- 12 infants who were not born at FSHC presented to Franklin Square Pediatric ED
- In total, 22 (32%) of the 69 infants who died presented to FSHC Pediatric ED
- 31 (45%) of the 69 deaths had contact with FSHC



Refining Prevention Efforts

- ❑ "Back to Sleep" is not enough
- ❑ The ABC message
 - Infants should be put to sleep
 - Alone
 - On their **Back**
 - In a safe **Crib**


Our Strategy: Consistent Messages

All Baltimore County partners have been using the same educational material

Healthy Babies Are Dying!

Sleep Safety Can Save Your Baby's Life

In the last year, many healthy babies have died as they slept. Don't let this TRAGEDY happen to your baby or a baby you care for.



Sleep Safety is as simple as ABC
 ALWAYS put me
Alone on my **Back** in a safe **Crib**

Follow these simple sleep safety tips EVERY TIME you put baby down to sleep

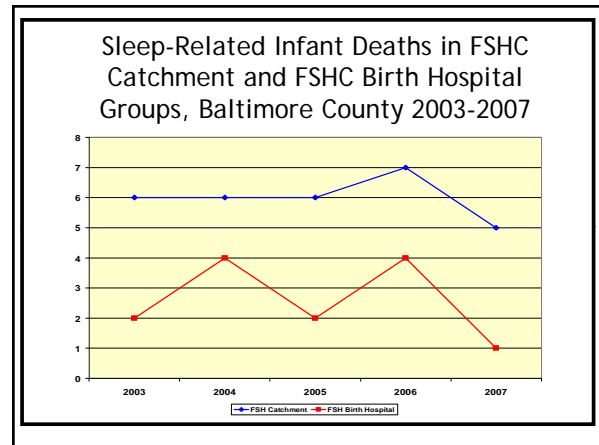
- ALWAYS put baby on his/her **BACK** to sleep
- ALWAYS put baby to sleep **ALONE**
- NEVER with other babies, children, adults, or pets
- ALWAYS put baby in a **SAFE Crib** or Bassinet
- NEVER on a bed or waterbed
- NEVER on a sofa or chair
- NEVER with pillows, quilts, or comforters
- ALWAYS keep the crib **CLUTTER FREE**
- NO bumpers, toys, animals, or clothing

Please use this LIFESAVING information today!

Our field-tested message is available in English and Spanish

FSHC Hospital-based Efforts

- ❑ Similar to Abusive Head Trauma (AHT) prevention program, all parents of newborns receive sleep safety alert, education
- ❑ Started informally in 2005
- ❑ Prior to wider implementation, BCHD conducted a 2006 formative evaluation of staff "readiness to change"
 - Nurses receptive (had been doing AHT prevention)
 - Non-professional staff very receptive
 - Physicians and advanced practice nurses were least receptive group (although were positive)
 - *Influential Champion* at FSHC identified as having facilitated readiness



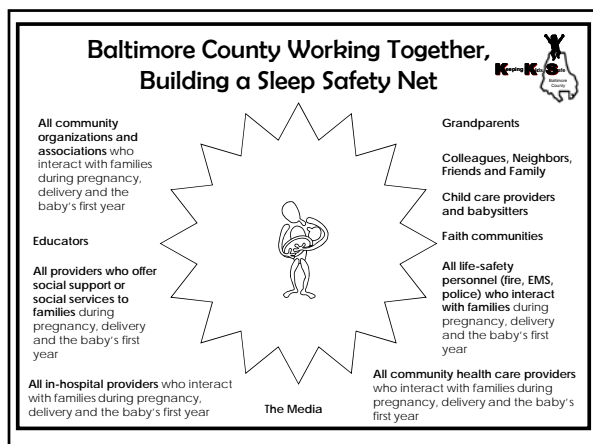
FSHC Hospital-based Efforts

- ❑ Appeared that giving info was working in 2007, but 3 deaths in 2008
 - Need to increase intervention intensity
- ❑ FSHC has just expanded prevention efforts to use of the brochure plus:
 - Signed commitment statement
 - Video (almost out there)

This is now an exact replica of AHT prevention efforts which started in 2002

Sleep Safety Summary

- ❑ **Healthy babies** are dying in their sleep
- ❑ Most significant preventable cause of death in infants
- ❑ Need to evaluate prevention efforts
 - Strategies, Program Fidelity and Outcomes
- ❑ Despite progress, the challenge of changing entrenched beliefs is significant
 - Professional
 - Community
 - Home
 - Religious
 - Cultural
 - Advocacy (*La Leche League*)



Understanding and Preventing
Sleep-Environment-Related Deaths in Infancy

Discussion

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E-mail your question/comments