Infant Safe Sleep: What Parents Believe

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Overview

- Definition of SIDS and Sleep-Related Deaths
- Statistics
- Why parents do what they do
- How do we respond to parents?
Definitions

- **SUID = Sudden and unexpected infant death**
  - Aka Sudden and unexpected death in infancy (SUDI)
Sleep-Related Deaths

• Most SUIDs occur during sleep or in sleep environment = Sleep-related deaths
  – Suffocation, strangulation, entrapment
  – Undetermined/ill-defined/unknown
  – SIDS
SIDS

• Any SUID (i.e. sudden and unexpected death) that remains unexplained after:
  – A complete review of the history
  – An autopsy
  – A death scene investigation

• Typically a seemingly healthy infant is found dead after a sleep period, dying either during sleep itself or during a transition from sleep to waking.

• A diagnosis of exclusion
• SIDS is not predictable
Suffocation

- **Asphyxia** is any situation in which there is a decrease in oxygen \((O_2)\) and an increase in carbon dioxide \((CO_2)\) in the body.
  - If you stop breathing
  - If your mouth, nose, or airway becomes obstructed.
  - If you “rebreathe” (imagine an infant face down in soft bedding).

- **Suffocation** is a form of asphyxia

- **Entrapment** is when an infant is “trapped” in a situation that produces asphyxia

- **Strangulation** is when bed clothes or other material is wrapped around the neck, blocking the airway causing asphyxia.
It does not take a lot of pressure to completely obstruct an infant’s airway
SIDS and Asphyxia

- Asphyxia has always been part of SIDS
- Many risk factors are associated with potentially asphyxiating environments
  - Prone sleeping
  - Soft bedding, pillows, bumper pads, etc.
  - Bedsharing
- Some asphyxial situations would cause death in any baby
  - In some, not all babies die
- Why do these babies die?
Triple Risk Model

Brainstem dysfunction, Arousal defect, Gene polymorphism

Prone sleep position, smoke exposure, soft bedding

Highest risk at 2-4 months
Behavioral, Sociocultural, and Environmental Factors

Genetic Factors

Phenotype

SIDS
Our current hypothesis is that SIDS results when a vulnerable infant cannot adequately defend against an asphyxiating environment — a level of asphyxia where most infants would not die.
Rebreathing Theory

• Infants in certain sleep environments are more likely to trap exhaled CO$_2$ around the face
  – Lie prone and near-face-down/face-down
  – Soft bedding
  – Tobacco smoke exposure

• Infants rebreathe exhaled CO$_2$

• Infants die if they cannot arouse/ respond appropriately
Brain Dysfunction

• Kinney at al have found abnormalities in autonomic control in the brainstem
  – Decreased neurotransmitter (serotonin, acetylcholine, glutamate, GABAA) binding
  – Network dysfunction
  – Infants may not be able to sense and respond to hypercarbia or hypoxia

• Weese-Mayer and others have found polymorphisms in serotonin transporter protein gene

• Up to 70% of SIDS have neurotransmitter abnormalities
• These abnormalities are not present in infants dying of other causes, including chronic hypoxia
Medullary level of the brainstem

Adapted from Kinney and Thach, 2009
Infant vulnerability and positional asphyxia

A safe sleep environment can reduce the incidence of both SIDS and Accidental Suffocation

Interactions can occur anywhere along the continuum

COMBINATIONS OF SIDS RISK FACTORS
- Prone sleep, soft bedding, over-bundling, head covered, bed sharing

The position of the threshold between a diagnosis of SIDS or Accidental Suffocation is determined by the medical examiner based on history and death scene investigation.

CLEAR EVIDENCE FOR ACCIDENTAL SUFFOCATION

Shading indicates the probability of death. Darker shades = increased probability of death.

SIDS Rate and Infant Sleep Position, 1988-2010
(Deaths per 100,000 live births)
Increasing rates of other sleep-related deaths

- Accidental suffocation
- Entrapment
- Undetermined
- Most (80->90%) of these occur in unsafe sleep environments
  - Bedding
  - Bed sharing with others
Rates of SIDS and SUlD


Deaths/100,000 Live Births

Year

Source: CDC Wonder, 2013
ASSB rates per 100000 live births, United States, 1984-2004


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Why is SUID increasing?

- **Diagnostic shift**
  - Improved death scene investigation
  - Deaths previously called SIDS now called something else

- **Increases in prone sleeping**

- **Increases in soft bedding use**

- **Increases in bed sharing** (particularly with multiple people, bedding, etc.)

- **80->90% of sleep-related deaths occur in unsafe sleep environments**
  - Bedsharing
  - Bedding
Black vs Non-Black Prone Prevalence and SIDS Rates

Sources: National Center for Health Statistics, National Infant Sleep Position study
Prone Prevalence by Race/Ethnicity

NISP, 2008
In homes across the country, parents like Mrs. Stanciu are mounting a minor mutiny against the medical establishment. For more than a decade, doctors have advocated putting babies to bed on their backs as a precaution against sudden infant death syndrome, or SIDS. Increasingly, however, some new parents are finding that the benefits of having babies sleep soundly - more likely when they sleep on their stomachs - outweigh the comparatively tiny risk of SIDS.
Shhh...My Child Is Sleeping (in My Bed, Um, With Me)

By TARA PARKER-POPE
Published: October 23, 2007

“Ask parents if they sleep with their kids, and most will say no. But there is evidence that the prevalence of bed sharing is far greater than reported. Many parents are "closet co-sleepers," fearful of disapproval if anyone finds out, notes James J. McKenna, professor of anthropology and director of the Mother-Baby Behavioral Sleep Laboratory at the University of Notre Dame.”
West Virginia data

- West Virginia ranks 38/50 in infant mortality among US states
  - IMR 7.64/1000 LB, compared to the national rate of 5.96.
- There were 37 SUIDs in 2013 – one every 10 days!
- Accidental suffocation or strangulation in bed is #1 cause of injury-related infant death in WV
FOR IMMEDIATE RELEASE
October 23, 2007

CITY OF PHILADELPHIA

DHS AND HEALTH DEPARTMENT LAUNCH NEW CAMPAIGN WARNING TO PARENTS ABOUT THE DANGERS OF UNSAFE INFANT SLEEPING ENVIRONMENTS

43 Infant Deaths In Past 18 Months Spur New Public Outreach Campaign

“From January 2006 through August of this year in Philadelphia, 43 infants have died in unsafe sleeping environments, defined as the baby co-sleeping with an adult or older sibling, being placed on an unsafe sleeping surface (sofas, cushioned chairs, or cluttered cribs), or sleeping in the presence of tobacco smoke. Over the past 18 months, more Philadelphia infants have died in unsafe sleeping environments than have died from physical abuse over that same time span.”
Parents warned about sleeping with infants

L.A. County officials says the increasingly popular practice known as 'co-sleeping' can have tragic consequences.

By Rong-Gong Lin II, Los Angeles Times Staff Writer

April 24, 2008

In 2006, 44 infants died while sleeping with an adult (76% increase from 2005)
“Last year, the city medical examiner's office recorded that 19 otherwise healthy infants died from these factors, up from 14 in 2007. The majority of those deaths were caused by suffocation after an adult or other child rolled onto the baby while in a bed, or the child was unable to breathe in adult bedding such as pillows and blankets, said Michael Graham, chief medical examiner for the city. ‘The leading factor in why otherwise healthy children die is unsafe bedding and bed-sharing,’ Graham said.”
What’s the problem?

• Everybody thinks that his/her baby is the exception to the rule
  – Gastroesophageal reflux
  – Premature
  – “Bad” sleeper

• OR the rules don’t apply to their particular situation
  – “This only happens to other people”
  – “I pay close attention to my baby”
What do parents really think?

- Why do they do what they do?
- Why don’t they do “the safe thing”?
- Need to understand what parents are thinking
- Only then might we have a message that will resonate with parents
SIDS is RANDOM

• SIDS is fate
• SIDS is God’s will
  – Suffocation is preventable
• SIDS happens for a reason
• Do the best you can for your infant
• Worry about SIDS less pressing than daily concerns
Nothing I do can make a difference

• “I don’t really feel that it’s anything that I can [do to] avoid it. If [SIDS] is going to happen, it’s going to happen. And it don’t have anything to do with the suffocation and things like that, which you can avoid, of course. But I believe even though you do everything right, something could still happen.”

• “SIDS occurs, and that’s something that must have been meant to happen. I wouldn’t blame myself. I just feel like I’m doing the best thing for my son and that whatever I feel comfortable with doing for him. Because you can’t listen to everybody, you can’t listen to statistics, and you have to do what’s comfortable. As long as you know your baby, and know what your baby likes, and how he reacts to things, then I feel that’s the best way. For me, the stomach; that’s the best way.”
The recommendations are NOT PLAUSIBLE

- “If they don’t know why the babies died, why does it matter which way you laid your baby?”
- “[For me to use the back position,] I need a guarantee, 100%. The whole thing, not half, the whole thing.”
- “Children sleeping on their back and they still pass. So who’s to say that [sleeping on the back] is not the cause? They don’t really know.”
- “Public health information … every 10 years it’s like the opposite. Five years from now they could say ‘oh, we were wrong. Put them on their stomach. We were so wrong.’”
It needs to make sense...

- “For suffocation, yes, [I would believe sleeping on the back is best]. SIDS, they still don’t know what causes it. That’s why I said, not SIDS, but the fact of suffocation. They can suffocate if they sleep on their stomach.”

- “And the suffocation thing, with the pillows and things like that... I believe it’s just common sense. You got an infant baby in the crib or a bassinet; you’re not going to put all these decorative pillows in there. When it’s time for them to go to bed, you take those pillows out.”

- “The re-breathing, now that to me... would aid in me advocating for putting her on her back a little more, for that reason. You know what I mean, because of the whole re-breathing.”
If you’re VIGILANT, it’s okay

- Vigilance is the most important factor in preventing SIDS
- Better vigilance is why there is less SIDS in other communities
- If you are vigilant, you can place the baby prone
- Need for vigilance may cause parents to engage in behaviors that are high risk for SIDS
  - Bedsharing – especially if the baby is sleeping prone
Vigilance is the key

• “My baby sleeps in the bed with me, because I can keep checking on him. All I’ve got to do is open my eyes and check on him. I’m right there beside him so I can tell whether he’s breathing or not, you know.”

• “Of course we would always sit her right there. And I never put her in her crib on her stomach or anything like that. I never did that. It was just kind of always like on the couch, you know, if we be in the living room or something like that, and just looking over there at her or whatever, and she just slept.”
Infant Safety is Important to Parents

• **Supine position**
  – I can better tell if they’re breathing
  – SIDS/safety
  – Doctor or health care professional told me
  – Concern about suffocation or vomiting while prone

• **Prone position**
  – Concerns about vomiting or aspiration while supine
  – Baby doesn’t hit or hurt him/herself

• **Bed sharing**
  – Easier to keep an eye on baby

• **Soft bedding**
  – Bumpers to cushion slats
  – Pillows to protect against falls
Infant Safety

“That’s what I’m afraid of too. Like laying on his back, I did that a few times with the newest baby and I heard him. I had to run into the room. He was (making choking sounds) like he was choking and that scared me, you know…and I just rolled him back over, cleaned him up, and rolled him back on his stomach.”

“He won’t lay on his back, he won’t lay on his side, but he’ll lay on his stomach…And the thing is, yea, and it’s like if I lay him on his stomach, it’s like ok, I gotta go in here and run in here, jump to make sure he is ok… So it’s kinda hard to like lay him in his bed right now, so he sleeps with me.”

“And you know somebody might come into your house or something…And do something to your baby, you don’t know because you are out, but if somebody was to try to get your baby from under right there where you at, or come up on you while you right there asleep, you’ll know. You’ll know something.”
Infant Comfort is important as well

- **Prone position (always)**
  - Baby looks uncomfortable on back
  - Baby doesn’t sleep as well
  - Baby sleeps longer and better
  - Baby will roll to prone anyway

- **Bed sharing**
  - Baby sleeps better next to me
  - Crib is too big for the baby

- **Soft bedding**
  - The crib looks so hard without bedding
Comfort trumps Safety

• “I bought every book I could get my hands on ... And, I knew what I was supposed to do and I took the baby home, and told my mother you can not lay this baby on the stomach and she has to lay on her back, because the doctor said so, and I read the book and I know that’s what I’m supposed to do... [But] in a few weeks [when I was tired], I turned her over and let her go to sleep, and she’s been sleeping that way... I mean, I’m overinformed and I still put her on her stomach to sleep.”

• “My son don’t like his pack-n-play for some reason...I made it softer and everything...Because you know how that little bed part is? I put blankets... under it, and then put the sheet back over it to make it softer. It don’t work, so I put him in the bed with me.”
Others can influence the decision – but parents make their own decision

- Parents feel that they know their baby better than anyone and so feel that they are the ones who can make the best decision for their baby.
- Even if parents trust their pediatrician, they are comfortable making decisions counter their pediatrician’s recommendations if they feel that it's in the best interests of their infant.
Influence of others

• “This is my baby. And I got to raise this baby, and I got to be up all night. So my baby is going to sleep the way that he or she is going to sleep. Or you can come home with me tonight, and you’re going to stay up all night.”

• “I’m always going to go with me first. Like I said, listening to other people can get you screwed up sometimes in life, so your best bet is you and yourself. You should always be the first person that you listen to before you listen to anything else.”

• “A white person will take what the doctor say and they’re going to do it. If the doctor said put the baby on the back, that’s it, because the doctor said it. Black people, we are going to do what we think is best... You say, don’t do it, we’ll do it anyway.”
• Parents place a high priority on safety and comfort for their baby – and these are sometimes competing priorities
  – Need to address concerns about infant comfort (length of sleep) and vomiting/aspiration
  – Efforts to encourage roomsharing without bedsharing must address parent safety concerns
• Many families do not think that they need to follow SIDS risk reduction recommendations
  – Recommendations need to be “make sense” to parents
  – Recommendations need to be consistent
  – Recommendations need to stress the “preventability” of infant death
What should we do?

- Everyone is an exception.
- How can we encourage behavior change in a way that is positive?
- Working smarter, not harder
Three categories of interventions

- **Awareness**: public health campaigns
  - Standardized, blast messages

- **Reinforcement**: answering frequently asked questions; consistent messaging
  - Individualized, but standardized messages

- **Problem Solving**
  - Individualized, focused on making it work
  - Requires knowledge of the barriers
  - Requires a conversation
Diffusion of Innovations

Category #1: Awareness

Category #2: Reinforcement

Category #3: Problem Solving
Category #1: Awareness

- Increase awareness of safe sleep practices through public health messaging and education materials
- Address challenges to consistent safe sleep messaging in the media & consumer environment
- “Blast” messages
- Not personalized
- Examples:
  - Back to Sleep campaign
  - Text4Baby
  - B’more for Healthy Babies
    - Tries to find messages that resonate – “This can happen to anyone, including you”
Awareness messaging: Advantages

- Well established
- Easy to implement
- Reaches large part of population (innovators, early adopters, late adopters)
- Begins to create a cultural norm and expectation
Awareness messaging: Disadvantages

• Sound bites
• Not nuanced
  – Example: “no bedsharing” = “sofa sharing is okay?”
  – “no bedsharing” = “what if I’m breastfeeding?”
• People feel that it doesn’t apply to them
• “Noise” in the media and popular culture that is inconsistent with safe sleep practices
• Controversy about and push back against scare message tactics
Category #2: Reinforcement

• Transmit knowledge about safe sleep practices to professionals who interact with expectant and new parents
  – Health professionals (physicians, nurses, childbirth educators, lactation consultants, home visitors, WIC, pharmacists)
  – Fire fighters
  – Child protective service providers
  – Child care providers

• Support the implementation of safe sleep practices in these settings through policies, accreditation, and legislation

• Interactive but standardized
Reinforcement interventions: Advantages

• Train the “trainer” (i.e., professional), who then trains parent

• Consistent messaging
  – Evidence shows that parents are more likely to follow recommendations if the messaging is consistent
  – More people with same messages = increased adherence
Reinforcement interventions: Disadvantages

• Training and increased knowledge ≠ Change in attitude and practice
• Still a single message; not nuanced
• Unregulated professionals (e.g., child care providers)
• Most interventions are focused on a single service sector even though many of the families in high-risk communities are served by multiple programs
Category #3: Problem Solving

• Focus on populations at highest risk
  – African Americans
  – AI/AN

• Special concerns
  – Breastfeeding
  – Bedsharing
  – Smoking cessation

• Interventions that reach non-primary caregivers with consistent messages and practices
  – Grandparents
  – Babysitters

• Identify and address barriers

• Provide strategies and products that remove obstacles to practicing safe sleep

• Build a sense of efficacy
Example: breastfeeding mother who wants to bedshare

• We know the evidence against bedsharing
  – Overheating
  – Soft bedding
  – No safety standards for adult mattresses
  – No study has ever shown a protective effect of bed sharing on SIDS
  – Risk of entrapment, accidental suffocation and strangulation
  – Predominant risk factor for sleep-related deaths in infants <4 months (Colvin, 2014)
  – Most studies on bed sharing have only looked at SIDS, not at other deaths
But is a breastfeeding mother a special case?

• Breastfeeding mothers are generally low risk
  – Older, higher SES, more educated
  – Non smokers
  – Do not drink alcohol as much
  – Do not usually use drugs (illicit and legal)

• Breastfeeding confers protection against SIDS
  – Doesn’t that cancel out the risk of bedsharing?
Breastfeeding and bedsharing

- In Ostfeld’s study, 25% of bedsharing deaths were breastfed (exclusively and partially breastfed) infants
  - Younger (median 45 vs 97 days of life)
  - More bedding risks (64.7% vs. 45.1%)
  - Less likely to be prone (11.8% vs 52.9%)
  - Less likely to be exposed to maternal smoking (33% vs 66%)
How can we make bedsharing safer for the breastfeeding mother (and other mothers)?

- No large-scale, epidemiologic data for breastfeeding mothers
- Breastfeeding does not cancel out the risk of bedsharing
  - There is still a risk for those <3 months of age
- There are no data about what makes bedsharing safer
- Sleeping with the baby on a separate surface next to you is the safest
- Recommendations for making bedsharing safer are extrapolated from solitary sleeping infants
Ways to potentially, maybe make bedsharing safer...

• Use a firm, flat mattress without mattress topper or memory foam.
  – No waterbeds, air mattresses, couches, or armchairs

• No pillows, comforters and other soft bedding
  – Ensure that the baby’s head and face are not covered.
  – Do not use pillows or other soft objects to try to prevent the infant from falling out of bed or getting caught between the mattress and headboard or footboard.

• Do not cover the infant with loose bedding.
  – An alternative is to use infant sleep clothing such as a wearable blanket.

• Place the infant on the back for sleep.

• Bed sharing should be with mother or parents only.

• It is safer to breastfeed in bed than to move the infant to a sofa or armchair to feed.
Problem Solving Interventions: Advantages

- Personalized: “for my baby”
- Can be more nuanced
- Family-centered
- Can be more culturally sensitive
Problem Solving Interventions: Disadvantages

• The “solution” that everyone agrees on may not be the safest solution
  – Example: you may not get a parent to stop smoking, but you may be able to get her to smoke fewer cigarettes
  – Weigh risks vs benefits
• Risk of sending inconsistent messages
• Little data on this yet
Other thoughts about how to make the message more appealing (or less unappealing)…
Knowledge about disease

• What disease(s) are we talking about?
  – SIDS
  – Suffocation and other sleep-related SUIDs

• How do the recommendations relate to the disease?
  – Do I understand why this works?
  – Do I believe that if I do this, it will make a difference?
Building a sense of efficacy

- Low self-efficacy => Poor adherence
  - SIDS is “God’s will” or “fate”

- SIDS vs Suffocation
  - Higher self-efficacy for suffocation prevention
  - Will that change behavior?
Persuasion

- **Is my baby susceptible to the disease?**
  - How common is it?
  - Do people whom I trust (pediatricians, nurses) as authority figures talk to me about it?
    - If they don’t talk to me about it, it’s either not that common, it’s not that important, or they don’t think that my baby is at risk
  - Do these authority figures say the same thing?
It helps if the message is consistent

• Health care professionals
  – “When I was in the hospital, the nurse put my baby on her stomach…if it’s so important, how come the nurse isn’t doing it?”

• Media
  – If I’m not hearing about it, it must not be safe anymore

• Advertisers
  – If the stores are selling it, it must be safe
In order to persuade, you need to know your audience.

“You’re not allowed to use the sprinkler system to keep your audience awake.”
Why parents may not embrace your words

- Risky behaviors may be perceived as being important practices (culture, tradition, safety)
  - Bedsharing
  - Prone sleeping to avoid aspiration
- Risky behaviors may be important coping mechanisms
  - Smoking
  - Alcohol use
- Risky behaviors may be unavoidable
  - No money to purchase a crib
- Very little perception of risk from SIDS
Every parent wants two things...

- Every parent wants his/her baby to be
  - Safe
  - Happy
- You are only as happy as your least happy child
- Your message needs to be consistent with these 2 goals
It’s a SALES JOB…

• **Roomsharing without bedsharing**
  – Crib next to parents’ bed
  – Can be vigilant and keep eye on baby, but don’t have to worry about pillows and blankets that are in your bed
  – Don’t have to worry about baby falling off

• **Pacifier: helps to soothe the baby**

• **Know what the perceived disadvantages are and be able to explain why they’re not problems**
Fear of choking/aspiration

• How do you know when a baby is choking?
  – Coughing or gagging (normal protective gag reflex) often misconstrued for choking or aspiration.

• Increased concern for aspiration with GE reflux
  – What percentage of babies reflux?
Aspiration/choking and sleep position

- No increased incidence of aspiration since the change to supine sleeping. (Byard 2000, Malloy 2002, Tablizo 2007)
Sleep position and Reflux

• Supine does not increase the risk of choking and aspiration in infants, even those with GE reflux
  – Protective airway mechanisms

• Infants with GE reflux should be placed supine
  – RARE exception: infants for whom the risk of death from complications of GE reflux is greater than the risk of SIDS (i.e., those with upper airway disorders, for whom airway protective mechanisms are impaired).
  – Examples: infants with anatomic abnormalities (e.g., type 3 or 4 laryngeal clefts, who have not undergone antireflux surgery).

• Elevating the head of the infant’s crib while the infant is supine is not recommended.
  – Ineffective in reducing GE reflux
  – Infant may slide to the foot of the crib - may compromise respiration.
But the baby sleeps better...

- Prone babies have higher arousal thresholds, sleep longer and deeper
But is it really BETTER?

- This increased arousal threshold may be dangerous, as arousal may be the issue surrounding SIDS…
- Need to change definition of a “good” sleeper
Baby’s leg gets caught in crib slats

- Keeps legs from going into slats
- Eliminates loose blankets
- WIN-WIN
Consider the barriers…

• Which ones can you help with?
  – Financial barriers: free crib programs
  – Space barriers: portable crib/playpen, re-arrange furniture in room so crib can fit?

• Some barriers are more difficult – culture, tradition, need for longer sleep

• Unanswered questions
  – Is there a way to bed share safely?
  – Can you compensate for one “bad” behavior with other “good” behaviors? (example: okay to sleep prone if use pacifier)

• Sometimes there are no good answers
Moving forward

• We need to understand why the community is not embracing safe sleep recommendations
  – Perceived barriers/costs
  – Misconceptions
  – It doesn’t make sense to them
  – It’s not important to them

• We need to make sure that our message
  – Makes sense
  – Is consistent
  – Explains the advantages
  – Addresses misconceptions
THANK YOU