

Strategies for SIDS Risk Reduction



Family-Centered Strategies for Health Care Providers

Definition of SIDS

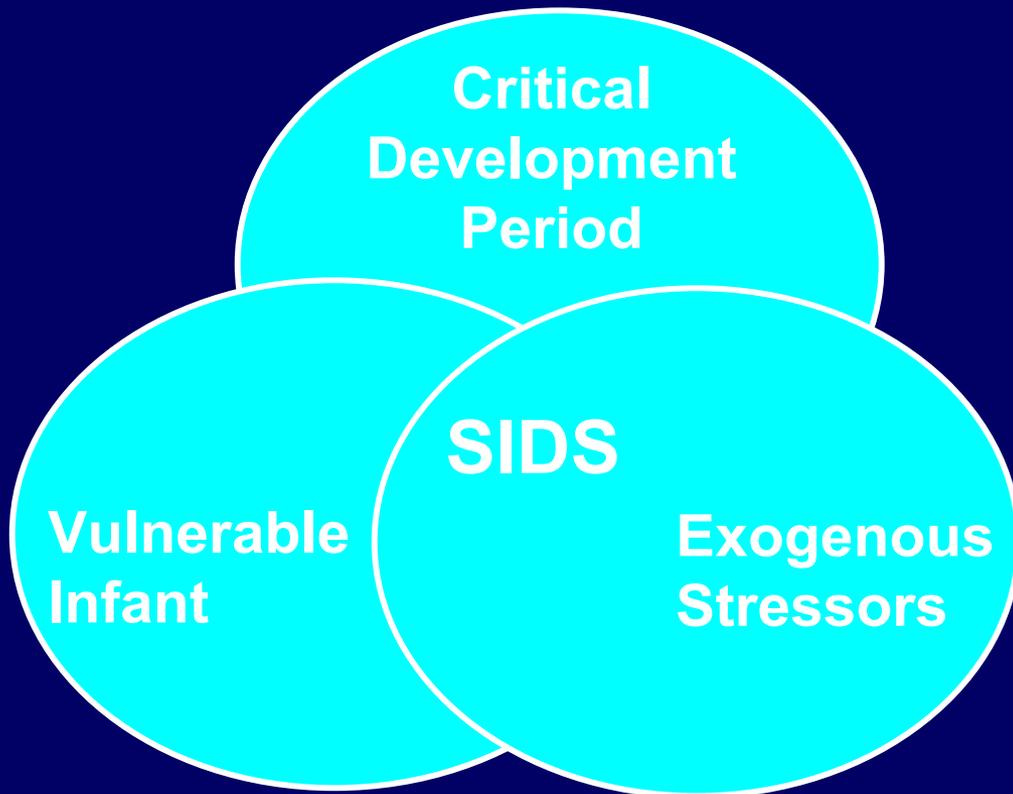
Sudden Infant Death Syndrome (SIDS) is the sudden death of an infant under one year of age, which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history.

Characteristics of SIDS

- Peak incidence at 2 to 4 months of age
- Slight male predominance
- More prevalent in cold, winter months
- Not considered genetic or hereditary
- Not due to suffocation, aspiration, abuse or neglect

What Causes SIDS?

Triple-Risk Model



Researchers believe there is probably more than one cause of SIDS, and that babies who die of SIDS are born with abnormalities which make them susceptible to sudden death at critical developmental periods. The vulnerable infant is met with an environmental challenge at a critical developmental period and cannot respond adequately, resulting in immediate death.

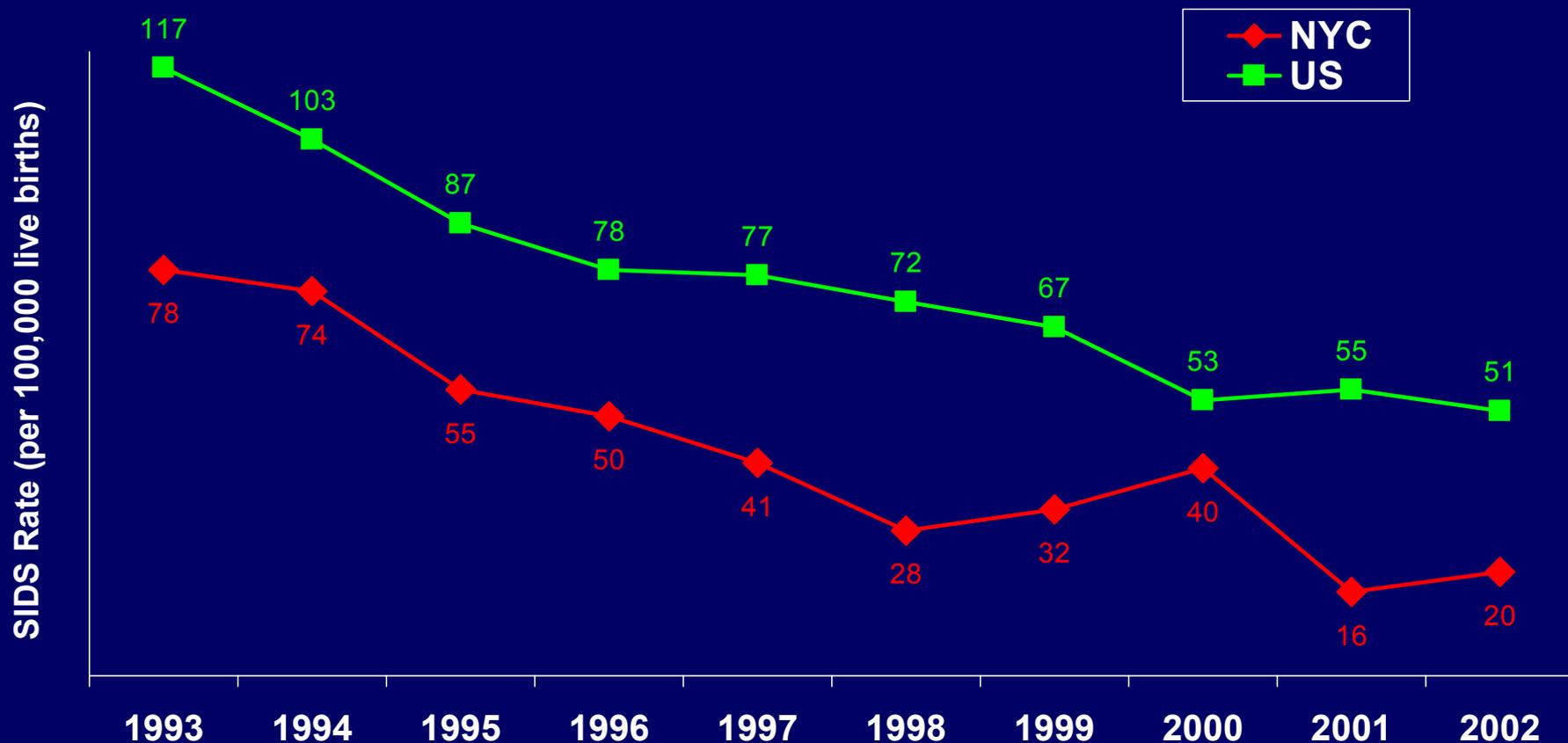
Risk Factors for SIDS

- Prone sleep position for infants (stomach sleeping)
- Lack of (or late) prenatal care
- Maternal age below 20 (adolescent mothers)
- Maternal substance use during pregnancy
- Low birth weight, premature and multiple-birth infants
- Exposure to cigarette smoke (prenatal and postnatal)
- Low socioeconomic status

SIDS in the United States

- Trends in SIDS
 - SIDS is the 3rd leading cause of infant mortality in the U.S.[†]
 - SIDS remains the number one cause of death for infants from one month to one year of age.[‡]
- SIDS Disparities
 - In 2002 the SIDS rate for infants of black mothers was more than double that of non-Hispanic white mothers.[†]

SIDS Rates: NYC and U.S. 1993-2002



SIDS in New York City

- Trends in SIDS

- SIDS rates in NYC have been decreasing in recent years.†
1990 → 96.7 2002 → 19.5
- Some of this decline is likely due to improvements in infant death investigations and forensic studies implemented in recent years

- SIDS Disparities

Based on NYC SIDS cases reported to DOHMH in 1999-2002:

- SIDS death rates (per 100,000 live births) are substantially higher among Black non-Hispanics and Hispanics§

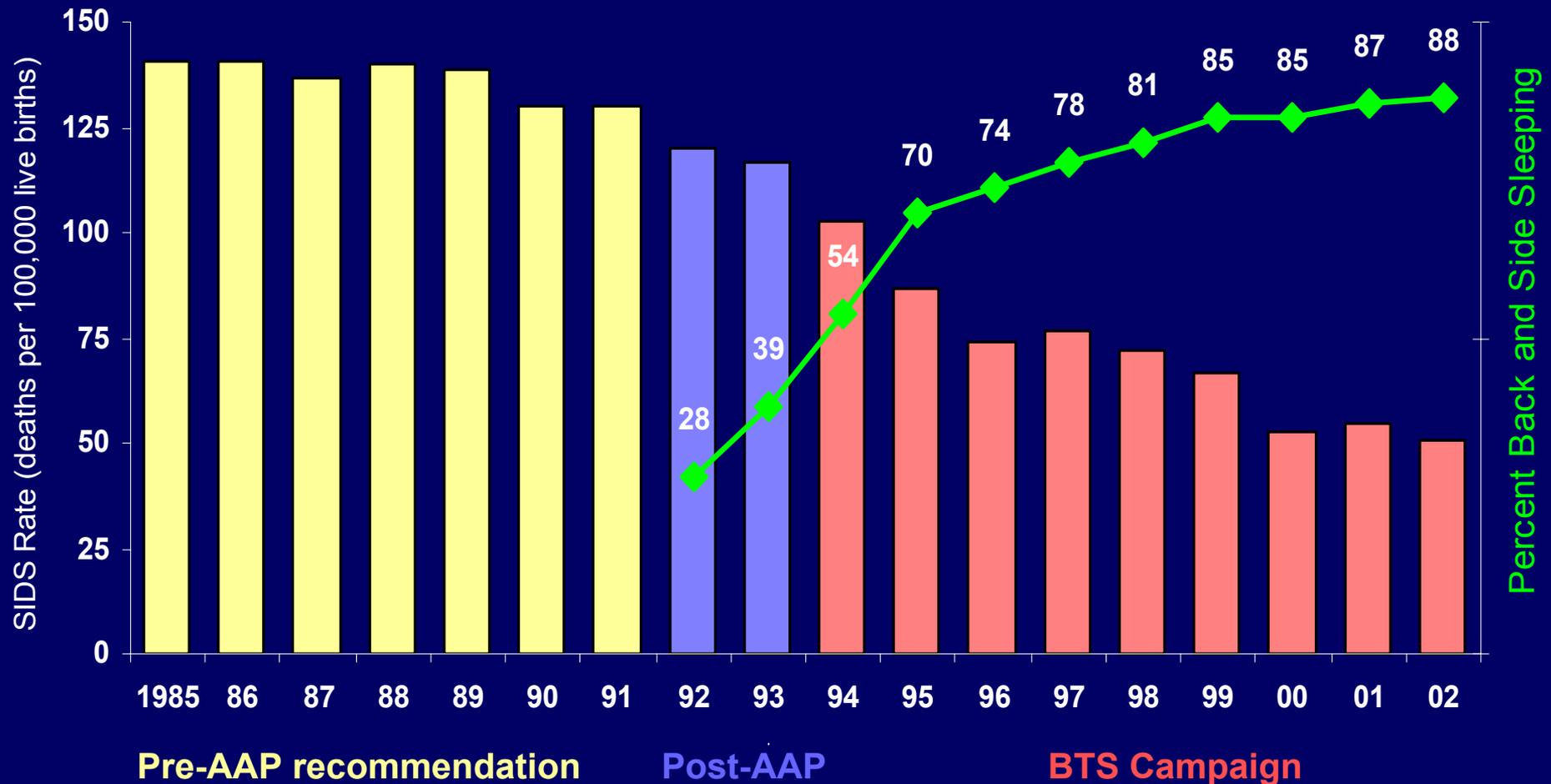
➤ Black non-Hispanic	54.4
➤ Hispanic	29.3
➤ White non-Hispanic	5.5

SIDS in New York City

A DOHMH review of 2000-2001 cases found that . . .

- Two-thirds of SIDS deaths in NYC were to mothers 24 years of age and younger
- NYC SIDS infants were:
 - Cared for by extended family or babysitter/ daycare at time of death..... 48%
 - Found in adult beds or sofas..... 32%

SIDS Rate and Sleep Position 1985-2002

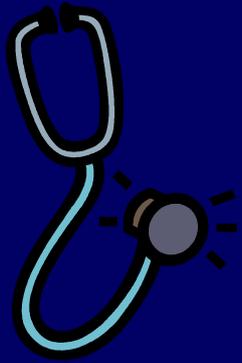


Studies on Back-To-Sleep Positioning

- **Infant Care Practices Study[†]** (Corwin 2003)
 - Recommendations to use supine position have not reached black and Hispanic families, families of low-income, and mothers with less than a high school education.
 - Prone sleeping was used by 21% of black and Hispanic non-college graduates - compared to 3% of white college graduates and 11% of black and Hispanic college graduates.
- **Chicago SIDS Risk Reduction Education Program Study[§]** (Rasinski 2003)
 - Educational message was not reaching the Black community
 - Implemented a back-to-sleep intervention targeted at the Black community (WIC-based presentations, provider training, church and community-based education)
 - The intervention was successful at changing sleep position practices among this population.

Disparities in Sleep Position: New York City

- The NYC DOHMH Community Health Survey (2003) found that 36% of Blacks reported putting infants to sleep on their stomachs, compared with 11% of other NYC respondents.[†]
- 43% of SIDS deaths in NYC (2000-2001) were infants who were placed to sleep on their stomach or side.[§]
 - Of these SIDS deaths, 52% were Black, 45% were Hispanic, and 3% were white non-Hispanic.[§]



Sleep Position in the Health Care Setting

- Research indicates that many infants are not placed to sleep on their backs in newborn nurseries, and nursery staff do not uniformly recommend the back-to-sleep position to families.[†]
- According to recent studies, parents are more likely to place infants to sleep on their backs if they received specific advice from a clinician, or if they observed nursery staff implementing the back-to-sleep position.^{†,‡, §}



Sleep Position in the NICU

- Unless otherwise recommended for medical reasons, all infants should be placed in the back-to-sleep position – even NICU infants
- Avoid placing large stuffed animals in the NICU crib that may pose a suffocation risk for the infant
- Nursery staff should implement an in-hospital transition to the supine position towards the end of the infant's stay
 - Integrate supine position into discharge planning

SIDS Focus Groups: Overview

Objective: In January 2004, NYC DOHMH/BMIRH conducted 6 focus groups in Harlem and Brooklyn to gain insight into the knowledge, beliefs, and practices regarding SIDS and risk reduction behaviors, and main sources of parenting information.

Target Audience: Two-hour sessions were conducted for 3 groups:

1. Young mothers (age 18-22)
2. Young fathers (age 18-25)
3. Caregivers (age 40+)

Selection Criteria: Participants had to be Black (of African American or Black-Caribbean descent), who were taking care of an infant 12 months or younger.

SIDS Focus Groups: Findings

1) Back to Sleep is heard of . . . but not often used.

- Parents/caregivers do not use back-to-sleep position due to concerns of choking, poor sleep, discomfort for the baby (including shaking attributed to the baby’s “startle reflex”), and excessive exposure to light on baby’s face.
 - Many are not convinced that back-to-sleep reduces SIDS risk.
- Mothers received back-to-sleep education in hospital, but the majority switched from back to stomach sleeping after one week.
 - Due to baby’s discomfort and encouragement by one’s own mother to put baby on stomach
- Side sleeping is seen as a compromise between back and stomach sleeping.

SIDS Focus Groups: Findings

2) SIDS messages are generally known but seen as abstract – therefore, they are not convincing and not consistently practiced.

- Since the cause of SIDS is unknown, the credibility of risk reduction messages is often undermined.
- SIDS information, including risk reduction practices, is not well understood by participants.

3) Matriarchal family structure - caregivers are a very important source of health information.

- Grandmothers, aunts and other caregivers often have a major influence on decisions involving baby's care.
- They are considered to be experienced and non-judgmental.

SIDS Focus Groups: Findings

4) The most trusted sources of information on infant's sleep and general health are reported to be:

#1 Instinct and life experience

#2 Family members (primarily one's own mother)

#3 Doctors and medical establishment

5) There is a perceived disconnect between medical establishment and parents/caregivers.

- Providers seen as less available sources of advice, due to long waits and financial or bureaucratic challenges
- Providers seen as less trusted, due to negative past experiences and a belief that providers cannot relate to the patients, because many do not have children of their own.

6) Caregivers/parents believe vigilant supervision and constant monitoring can prevent bad things from happening to babies – such as SIDS.

SIDS Focus Groups: Findings

7) Bedsharing is extremely common, because it is considered to be associated with emotional closeness and improved supervision.

- Participants reported that bedsharing usually continues until baby is 3 to 4 months old.
- Parents/caregivers feel that baby is comforted by physical closeness, and they can closely monitor baby's breathing and needs.

8) SIDS education is often seen as unfairly targeting the Black community.

- They are unaware of, or unclear about, the disparity in SIDS deaths between Black and Caucasian babies.
- They feel that it feeds into a negative stereotype about Blacks.

Strategies for Providers

Target the following populations:

- Pregnant women during prenatal care visits
 - Start early! Provide education on sleep position, breastfeeding, SIDS risk factors
- Teen mothers
 - Educate them on SIDS risk factors and encourage them to seek support from family/social networks
- Alternate caregivers
 - I.e. grandparents, aunts/uncles, babysitters, day care, other caregivers
 - Communicate with the family network about risk factors, not only the mother

Strategies for Providers

- Emphasize that while the cause of SIDS is unknown, risk for SIDS can be reduced.
 - Remind parents/caregivers that SIDS rates have dramatically declined since the initiation of the 1994 AAP recommendation to put babies to sleep on their back.
- Make sure to incorporate cultural competence into your practice and/or institution.
- Be sure to include grandmothers, aunts and other caregivers in discussions about baby's care and SIDS education.
- Recognize and acknowledge the expertise of the parent/caregiver, i.e. what they are doing “right”.

Strategies for Providers

- Ask the parent or caregiver what they know about SIDS and if they are aware of ways they can lower the risk of SIDS.
- Address and dispel common myths and misconceptions about SIDS.
- Communicate with the mother, family members, and other health care providers that side positioning is no longer recommended.
- Demonstrate the back sleep position to parents and caregivers during the visit, i.e. how to use the feet-to-foot method of placing the blanket.

Key Points to Communicate to Parents and Caregivers

- ✓ **Always place baby on his/her back to sleep, even for naps.**
 - Since 1994, it has been recommended that babies always be put to sleep on their back.*
 - This is the best way you can help reduce your baby's risk for SIDS. Even though the cause is unknown, it is known that infants put to sleep on their back are less likely to die of SIDS.
 - Even if bedsharing, make sure baby is sleeping face up.

Key Points to Communicate to Parents and Caregivers

- ✓ **Remove soft and fluffy bedding from sleep area.**
 - This includes pillows, quilts, toys, and stuffed animals.
- ✓ **Don't allow the baby to sleep on soft surfaces.**
 - This includes the couch, sofa, adult bed, waterbed, sheepskin or other soft surfaces.
 - Use a firm, tight-fitting mattress for the crib.
 - Make sure baby can't get trapped between the sofa cushions, mattress or framework of the bed or crib.

Key Points to Communicate to Parents and Caregivers

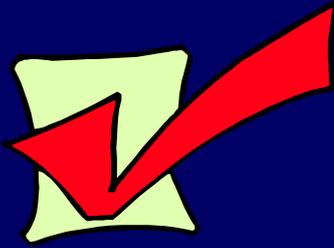
- ✓ **Make sure baby's head and face remain uncovered during sleep.**
 - Keep baby's mouth and nose clear of any blankets or coverings. If you must use a blanket, use the "feet to foot" method.
- ✓ **Don't let baby get too warm while sleeping.**
 - Babies should not be tightly bundled or "swaddled" in a blanket, even in hospital settings.
 - Remember that a baby's environment should be the same temperature that is comfortable for an adult, about 70° F.

Key Points to Communicate to Parents and Caregivers

- ✓ **Create a smoke-free environment for your baby.**
 - Don't smoke during pregnancy or after the birth of your baby.
 - Make sure that no one smokes around your baby.
- ✓ **Remember that “Tummy Time” is important when baby is awake and someone is watching.**
 - It can strengthen her neck and shoulders, and helps prevent bald spots and flat heads.

Common Myths To Dispel About SIDS

- SIDS is not caused by vaccines or immunizations
- SIDS is not contagious
- SIDS is not hereditary
- SIDS is not a result of child abuse or neglect
- SIDS, or “crib death”, is not caused by cribs
- Apnea monitors will not prevent SIDS



Always Ask . . .

Remember to ask these questions at all follow-up visits:

- In what position do you place your baby to sleep?
- Where does your baby sleep and with what kind of bedding?
- Does anyone in the household smoke cigarettes around the baby?
- What is the temperature of the room where your baby sleeps?
- Who else takes care of your baby? Do they follow the SIDS recommendations?

SIDS & Cultural Competence

- Identify predominant patient populations in your health care setting.
- Be familiar with their cultural, ethnic, and religious beliefs (i.e. pregnancy, infant care, sleep position)
 - **Ethnicity** – Views on health, medicine, disease, health providers
 - **Culture** – Traditional medicines, faith healers, etc.
 - **Religion** – Views on illness, etiology, fatalism
- Be sure to understand and respect the views of parents/caregivers – especially in the context of their culture and background
- Address language barriers through culturally-consistent staff and/or interpreters, as well as patient education materials in appropriate languages



Common Barriers To “Back-To-Sleep”

- Grandparents and other caregivers recommend putting baby to sleep on their stomach
 - This includes older caregivers as well as mothers who gave birth to their last child more than 10 years ago.
 - Ask them why they choose to use the prone position and address how to overcome these concerns.
 - Discuss how practices have changed over the years, re-educate caregivers. “Did you know that we are supposed to put babies to sleep on their backs?”
- A belief that baby will develop a permanent flat spot or bald spot on his head
 - Remind parents/caregivers that this is a passing condition that goes away after baby starts learning to sit up.
 - This can be avoided with “tummy time” – placing the baby on his stomach when he is awake and is being observed.

Common Barriers To “Back-To-Sleep”

- A common belief that baby can choke in the back-sleep position
 - Some caregivers may need more intense education to dispel this misconception, since this is often one of their main reasons against using the supine position.*
 - Inform parents/caregivers that infants automatically swallow or cough up fluid. The number of babies dying on their backs has not increased since the initiation of the Back-to-Sleep campaign in 1994.
- A belief that babies sleep better on their stomachs
 - Most babies get used to the back position quickly. The earlier you put baby on his/her back to sleep, the more quickly baby gets used to it.
 - Babies sleeping on their stomachs may not wake up as quickly if something is wrong.
 - Reassure them that the “startle reflex” is a normal reflex in baby’s development. Parents can comfort baby by putting her to sleep on their chest, and then laying sleeping baby on her back in the crib.

Common Barriers To “Back-To-Sleep”

- Baby gets too cold at night, or kicks off the blanket during sleep
 - Remind parents/caregivers to use the “feet-to-foot” method in the crib - where the baby’s feet are at the bottom of the crib, the blanket is no higher than the baby’s chest, and the blanket is tucked in around the crib mattress.
 - “Sleep sacks” can also be used to keep baby warm.
- They put the baby to sleep on his side or stomach in the hospital
 - Studies have found that back-sleeping is the safest position for infants, even safer than side sleeping.
 - Side sleeping increases babies’ risk of rolling to the prone position.

Breastfeeding and SIDS

“According to AAP, evidence is insufficient to recommend breastfeeding as a strategy to reduce SIDS.”

*– AAP Task Force on Infant Sleep Position and SIDS, Pediatrics 2000**

- Although several retrospective studies have demonstrated a protective effect of breastfeeding on SIDS, other analyses and prospective cohort studies failed to find such an effect after adjustment for confounding variables.*
- However, breastfeeding is known to provide many other health benefits and should be practiced exclusively for at least the first 6 months.

Bedsharing: A Controversial Issue

“There are insufficient data to conclude that bedsharing under carefully controlled conditions is clearly hazardous or clearly safe.”

– AAP Task Force on Infant Sleep Position and SIDS, Pediatrics 2000

Risks¹⁻³

Research has shown that bedsharing may increase risk for SIDS in certain situations. This includes bedsharing with a parent who is:

- A smoker
- Under the influence of alcohol, drugs, or medications that may impair arousal
- Extremely tired or ill
- Obese

Benefits⁴⁻⁶

Some believe bedsharing may have certain benefits, such as:

- Increased breastfeeding
- Enhanced closeness between parent and baby
- Increased awareness of parent to infant's needs and arousals
- More infant arousals and less deep sleep for infant

* Note: No epidemiologic studies have shown that bedsharing has a **protective** effect from SIDS.¹

“Safer” Bedsharing

- If bedsharing, take care to observe the standard recommendations for **“safer” bedsharing**:
 - Nonprone sleeping
 - Avoidance of soft sleeping surfaces, loose adult bedding (i.e. pillows, quilts, comforters), overheating or overbundling, and entrapment by the bedframe, mattress, and/or wall
- As an alternative to bedsharing, parents may place baby’s crib near their bed for more convenient breastfeeding and parent contact.

Communicating with Patients About Bedsharing

- Keep in mind that bedsharing is a common practice in many cultures and households.*
- If parents decide to share a bed with the baby, make sure to discuss “safer” bedsharing practices.
- Parents and caregivers should not bedshare if the adult is a smoker, is very tired or ill, or is under the influence of substances (such as alcohol, drugs, or prescription medications) that may impair arousal.

Towards Eliminating SIDS



- Research is in progress to elucidate the etiology of SIDS . . . so we can develop other strategies.
- Back-To-Sleep works!
 - Providers must make back-to-sleep messages more consistent and understandable
 - Providers must anticipate and address barriers to risk reduction

SIDS Resources

New York State Center for Sudden Infant Death, New York City

Satellite Office / MHRA. nycsids.center@verizon.net, (212) 686-8854

- Bereavement support for SID families; SIDS & SIDS Risk Reduction education for health providers throughout NYC.

NYC DOHMH, Bureau of Maternal, Infant & Reproductive Health

www.nyc.gov/health/maternity, (212) 442-1740

National SIDS Resource Center. www.sidscenter.org, 1-866-866-7437

First Candle/SIDS Alliance. www.firstcandle.org, 1-800-221-7437

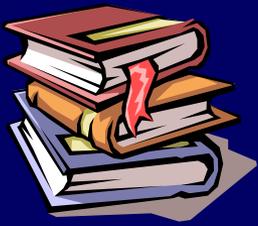
NICHD/NIH Back to Sleep Campaign. www.nichd.nih.gov/sids/sids.cfm

Association of SIDS and Infant Mortality Programs. www.asip1.org

National Center for Cultural Competence. www.georgetown.edu/research/gucdc/nccc

Consumer Product Safety Commission. www.cpsc.gov, 1-800-638-2772

- Information regarding crib safety guidelines



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