

# Educating Parents About the Risk Factors of Sudden Infant Death Syndrome

## The Role of Neonatal Intensive Care Unit and Well Baby Nursery Nurses

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Nurses in newborn nurseries and neonatal intensive care units are instrumental in educating parents about reducing the risk for SIDS. Nurse participation is acknowledged and encouraged in the current policy statement on SIDS Risk Reduction put forth by the American Academy of Pediatrics. Despite the decline in SIDS, it remains the leading cause of postneonatal infant mortality, and despite greater public compliance with the risk reduction guidelines there is room for improvement in how effectively and consistently they are disseminated. To facilitate nursing participation as educators, role models, and collaborators in the development of relevant hospital policies and procedures, we review the current recommendations, addressing issues that may serve as barriers to participation, describing the biological plausibility underlying risk-reducing practices, and presenting resources from which nurses may obtain teaching materials and model policies. **Key words:** *neonatal intensive care, newborn nursery, parent education, sudden infant death syndrome*

### WHAT IS SUDDEN INFANT DEATH SYNDROME?

Sudden infant death syndrome (SIDS) is characterized as the sudden death of an infant younger than 1 year of age that remains unexplained even after a complete autopsy, a death scene investigation, and a thorough review of the clinical history are conducted.<sup>1</sup> SIDS is a diagnosis of exclusion in which the cause of death

cannot be determined and for which no pathognomic features have been identified. The risk of an occurrence is increased by such factors as a premature birth, exposure in utero or infancy to tobacco smoke, or prone sleeping.<sup>2</sup> However, predicting with certainty which infants will die from SIDS is still not possible. Parents and caregivers typically report that in most cases the infant had been placed down for a nap or nighttime sleep and later found unresponsive; the infants had not cried out or showed any evidence of distress or pain or signs that something was wrong.

In 2004, the most recent year for which national mortality data were finalized at the time of this article's publication, there were 2246 deaths from SIDS (0.55 deaths per 1000 live births).<sup>3</sup> All population groups are represented. However, there are racial and ethnic disparities in the incidence of SIDS, with black and American Indian infants at the highest risk.<sup>4</sup>

SIDS remains the leading cause of postneonatal infant mortality in the United States, even though the incidence has declined by more than 50% since 1992.<sup>2</sup>

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Much of the decline in the incidence of SIDS has been associated with the dissemination by public health programs and health professionals and the application by parents and caregivers of risk reduction guidelines collectively known as the Back to Sleep campaign.

The role of the nurse in the newborn nursery and the neonatal intensive care unit (NICU) in enhancing parent knowledge and compliance is acknowledged in the current policy statement of the American Academy of Pediatrics on SIDS risk reduction.<sup>2</sup> Nurses are urged to implement these recommendations well before discharge since parents are influenced not only by what they are told but especially by what they observe being done by caregivers. Moreover, nurses especially are seen as role models in the caregiving of these infants.

### **RISK REDUCTION EDUCATION AND THE DECLINE IN SIDS RATES**

The Back to Sleep initiative reflects policy statements issued by the American Academy of Pediatrics (AAP), commencing in 1992, that are derived from a review of scientific evidence. These policy statements are periodically revised to reflect advancements in knowledge and are published in *Pediatrics*, the official journal of the AAP.<sup>2</sup> The current AAP SIDS policy recommendations, issued in 2005, including references for the underlying research, can be accessed on-line at [www.aap.org/healthtopics/Sleep.cfm](http://www.aap.org/healthtopics/Sleep.cfm).

Education to reduce modifiable risk factors such as nonsupine sleep is the most effective intervention currently available. Moreover, even as genetic predispositions for SIDS are identified, it appears that a gene-environment interaction must occur for the infant's vulnerability to be realized. For example, in a study of a cardiac sodium channel variant that may raise susceptibility to acidosis-induced arrhythmias in infants, the authors noted, "It is imperative to continue to support effective public health efforts to decrease known environmental risk factors (e.g., prone sleeping position). SIDS is argued . . . to result, like many common disorders, from a genetic predisposition that yields poor tolerance of common challenges to physiological homeostasis."<sup>5(p434)</sup>

### **THE TRIPLE-RISK MODEL FOR SIDS**

In 1994, Filano and Kinney presented a research hypothesis regarding SIDS described as the Triple-Risk Model.<sup>6</sup> The researchers postulated that sudden death could result if an infant with an underlying physiological vulnerability is challenged by an environmental

stressor during a developmental period in which potential compensatory mechanisms have not emerged. One area of potential physiological vulnerability now being studied is the serotonergic system of the brainstem, which helps regulate autonomic respiratory function. Potentially affected is the capacity to respond to life-threatening challenges such as hypoxia, asphyxia, or hypercarbia. Thus, a sleeping infant with a diminished ability to sense and physiologically react to dropping levels of oxygen would fail to become aroused, move, and generate protective cardiorespiratory changes. Using this model, it is possible to understand how prone sleep can exacerbate the infant's underlying vulnerability. During prone sleep, an infant is at risk for rebreathing oxygen-poor air trapped in an air pocket created by soft bedding. Prone sleep is deeper and more prolonged than supine sleep. Without an underlying disorder, the challenged infant would arouse and react to these environmental conditions and restore homeostasis. However, in association with an underlying disorder, the additional compromises to arousal may not be overcome.<sup>7,8</sup> Other known risk factors for SIDS such as tobacco smoke, infection, and prematurity also diminish the capacity to arouse to hypoxic challenges.<sup>9-11</sup> The third element of the Triple Risk Model is developmental and addresses the critical period during which an underlying physiological vulnerability is potentially most lethal. Although, by definition, SIDS can occur throughout the first year, it is most likely to occur between 2 and 4 months of life, with slight variation when adjusting for gestational age.<sup>2,12</sup> This peak period defines a developmental stage during which control of arousal cycles and autonomic function is undergoing great change.<sup>13</sup>

Paterson et al identified several neurotransmitter abnormalities that were more likely to be found in the brainstem of infants who died of SIDS. In 87% of these cases, both the defect and at least 1 risk factor for SIDS were present.<sup>14</sup> These findings provide biological plausibility for the risk reduction messages of the Back to Sleep campaign.

### **NURSING IMPACT ON PARENTAL KNOWLEDGE AND COMPLIANCE**

Overall, infants are more likely to be placed to sleep in the supine position if this recommendation had been provided by a healthcare professional.<sup>15</sup> For mothers of very-low-birth-weight infants, nursery practices were the most important factor in choice of position.<sup>16</sup> The recommendations of both the physician and nurse mattered.<sup>17</sup> However, compliance was greatest when

parents not only heard advice before discharge but also observed it in practice in the nursery.<sup>18</sup> Unfortunately, discrepancies exist between nursing knowledge and practice, with those in practice longer found to be less likely to believe in the association between SIDS and sleep position.<sup>19</sup> However, teaching programs can be effective in providing an understanding of the basis for the Back to Sleep policies. Such programs can help nurses recognize the impact of their discussions and role modeling on parental practices.<sup>20</sup>

The NICU poses a particularly challenging environment in which to teach parents about SIDS risk reduction. For much of their stay, infants may have been kept in the prone position. Prolonged exposure of parents to this model has been hypothesized to be one reason why very-low-birth-weight infants are more likely than larger low-birth-weight infants to be placed prone after discharge.<sup>21</sup> There is strong evidence that whatever the benefits are of prone sleep in the NICU, the risk of prone sleep after discharge is great. So too is the risk for SIDS from sleeping laterally. Fleming and Blair note, "The evidence is clear that for the overwhelming majority of preterm infants approaching discharge from hospital there are no significant disadvantages, and many potential advantages to the supine sleeping position."<sup>22(p162)</sup> This population is of particular concern because of the higher risk for SIDS deaths in premature infants<sup>23</sup> and the increasing number of births in this category.<sup>24</sup>

Lockridge et al<sup>25</sup> published one of the first articles on the need to develop NICU policies and procedures that met the simultaneous needs of developmentally appropriate care and SIDS risk reduction. In the appendix, we provide resources from which nurses may obtain model policies for NICUs and newborn nurseries as well as educational materials for parents. These materials suggest methods for integrating the newest SIDS risk reduction guidelines of the AAP with hospital policies and procedures, nursing protocols, and parent education. As with all policies, they are best achieved when nurses contribute to the development of their unit's policies and help design appropriate in-service programs to advance their knowledge of and confidence in these policies.

Aris et al developed a survey for assessing the status of nursing opinions and practices with respect to discharge teaching related to sleep position and SIDS.<sup>26</sup> They found that only 52% of neonatal nurses routinely provide instructions that are consistent with the promotion of supine sleep at home. The survey published in their article covers a wide range of issues related to sleep and thus can serve as a basis for identifying existing beliefs and practices upon which

in-service education programs and policy reviews can be built.

### ADDRESSING NURSING CONCERNS ABOUT COMPONENTS OF THE RISK REDUCTION GUIDELINES

To serve as role models and educators who promote SIDS risk reduction guidelines, nurses need to feel knowledgeable about the information they are presenting to families before discharge, reassured that any potential adverse consequences have been identified and addressed, and confident that the guidance is evidence-based and that the benefits outweigh any possible risks.<sup>27</sup> Yet, historically, the research and review articles and policy statements on SIDS are disproportionately found in medical rather than nursing journals. Without access to this information, nurses' concerns about the guidelines will remain a challenge to the provision of a consistent and evidence-based message to parents.<sup>28,29</sup> Nurses are therefore encouraged to participate in continuing education, to collaborate in multidisciplinary committees that share and update relevant information, and to develop evidence-based policies.<sup>25,30</sup>

One of the more commonly voiced concerns by nurses has been whether the supine position increases the risk of death from aspiration. This issue has been studied, and although there has been a welcome rise in the use of a supine sleep position for infants, there is no evidence of an increased risk of death from aspiration.<sup>31,32</sup>

Another concern relates to an increased incidence of positional plagiocephaly without stenosis. Without a population-based study of the incidence of any flattening at the back of the head, it is unclear if and by what degree plagiocephaly without stenosis is increasing or if a possible rise may reflect an increase in awareness as well as in true incidence.<sup>2</sup> However, even with the possibility of an increase in true diagnosis, the sections on Plastic Surgery and Neurological Surgery of the American Academy of Pediatrics Committee on Practice and Ambulatory Medicine continue to support the benefits of supine sleep.<sup>33</sup> The AAP policies also offer several suggestions for reducing the risk for developing positional flattening, including the use of tummy time for infants when they are awake and under supervision, the avoidance of too much time in such devices as car-seat carriers and bouncers, the use of upright "cuddle time," and shifts in the direction the infant faces while asleep. An additional benefit of tummy time is the promotion

of motor development, especially upper body muscle development.

Finally, general health in the infant appears to benefit from the supine sleep position. There were no increases in symptoms or illnesses in the first 6 months.<sup>34</sup> There were fewer cases of fever at 1 month, fewer stuffy noses at 6 months, and fewer outpatient visits for ear infections at both 3 and 6 months.

## THE 2005 AAP SIDS REDUCTION POLICIES<sup>2</sup>

Several important modifications have been made since the previous policy statement was issued in 2000.<sup>2,35</sup> Supine (back) sleep is now the exclusively recommended sleep position. The side position is more likely to be unstable,<sup>22,36</sup> and shifts to an unaccustomed prone sleep position result in an extremely high risk level.<sup>37</sup> The recommendation of the supine position for sleep applies both to term and preterm infants.

Second, a separate but proximate sleep environment for the infant is now recommended in place of bed sharing.<sup>2</sup> This controversial new policy is a response to the evidence of potential risks found in the bed sharing environment, as it is defined in this culture, and, perhaps, to the challenge of creating a sufficiently detailed and inclusive recommendation for reducing these risks.<sup>38,39</sup> Although concerns have been voiced about the potential impact of this policy on breast-feeding, a recent article in the *Journal of Human Lactation* recognized the intent of the policy and noted that lactation consultants should determine how best to provide support to women as they follow these guidelines.<sup>40</sup> While infants may be brought into the parent's bed for comfort or to support breast-feeding, they should be returned to a separate sleep surface (eg, a crib, bassinet, or cradle that meets the Consumer Product Safety Commission standards) when the parent returns to sleep. Infants should not share their bed with a sibling or other child. Nurses should review hospital policies concerning cobedding of multiples, as this practice provides a contradictory model. However, sleeping in the same *room* as the parent *is* recommended as data support the risk-lowering benefit of room sharing.<sup>41</sup>

Finally, pacifiers are now recommended for all sleep episodes.<sup>2</sup> To avoid having an adverse impact on breast-feeding, pacifier use by nursing infants should be postponed until 1 month of age. Pacifiers should not be reinserted once they fall out during sleep, nor should they be coated with sweet substances to prompt usage. If an infant resists, the parent should not force its usage.

Knowledge of the evidence-based rationales underlying these and the remaining recommendations will assist the nurse in understanding why they were developed. The policy statement includes a review of relevant research and can be accessed at the AAP Web site noted earlier.

In addition to the topics just reviewed, the 2005 policy affirms the importance of protecting pregnant women and infants from smoke exposure.<sup>2</sup> The policy statement also continues to support the use of a firm crib mattress. Soft materials such as pillows, quilts, comforters, or sheepskin should not be placed over or under a sleeping infant. Nor should these objects or other loose bedding be placed in the crib. Waterbeds, sofas, or other soft surfaces are not appropriate for sleep. A sleep sack may be used in place of a blanket. If a blanket is used, it should be tucked around the foot of the mattress and not reach beyond the infant's chest so that the infant's face is protected from being covered. A covered face, even in the supine position, is considered a risk factor.<sup>42</sup> The infant should not be overheated or overbundled. The room temperature should feel comfortable to a lightly clothed adult. Commercial devices that are sold to reduce the risk of SIDS have not been sufficiently tested to prove that they are safe or effective and so are not recommended.

## HEALTH BEHAVIOR CHANGE THEORY AS A TOOL FOR NURSES

An important element in changing health behavior is developing a relationship of trust with the parent and family. Nurses have a unique opportunity to achieve an effective patient-provider relationship with new parents and caregivers and thus educate and influence the family. By communicating conversationally with families, nurses can elicit and address any fears and concerns that may serve as barriers to compliance. Behavior change is more likely to occur if providers use nonjudgmental responses to beliefs associated with culture-based infant care practices. Once cultural and personal beliefs are shared, correct information regarding SIDS risk reduction practices can be discussed in this context and potential concerns elicited and addressed.

By asking specific questions during hospitalization and at discharge, the nurse will be able to tailor and thus personalize SIDS risk reduction education. Who will provide care to the baby? What bedding will be used? Does anyone in the home smoke? Where and in what position will the infant sleep? Baseline awareness of SIDS risk factors can thus be determined,

and the nurse and family can work collaboratively to improve safety. Thus, if a grandparent will serve as caregiver, it will be important to work with the family to discuss risk reduction with this essential family role model.<sup>43</sup>

Nurses can also guide families by pointing out the reasons for any temporary discrepancies between hospital-based practices related to care and what will be recommended for SIDS risk reduction as the hospitalization ensues and discharge occurs. In the context of the trusting relationship, nurses can thus eliminate confusion about what parents are being advised to do at home.

Black infants are more likely than infants from other racial groups to be placed in the prone position after discharge.<sup>42,43</sup> The greater use of prone sleep is but one of many factors which may contribute to the racial disparity in SIDS.<sup>5,36,44-46</sup> Given the value families place on nursing guidance, nurses have a unique opportunity to use their role to promote awareness of the modifiable risk factors for SIDS by all racial and ethnic groups.

## SUMMARY

The incidence of SIDS has declined in the era following the dissemination of AAP guidelines for SIDS risk reduction. Research is improving our understanding of the biological plausibility of risk factors and thus underscores the importance of maintaining risk reduction education. Parents are more responsive to these messages when there is consistency in the information from healthcare providers and when these infant care practices are observed in the hospital. Culturally competent communication responsive to specific issues helps build trust between mother and provider and reinforces the message. By understanding the evidence underlying the AAP risk reduction guidelines and methods for health behavior change, by supporting the development of nursing policies that advance these behaviors, and by serving as models as well as educators, hospital nurses can help affect parenting behaviors and ultimately the health and safety of infants and children.

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## Appendix

### Resources

1. American Academy of Pediatrics: The Task Force on Sudden Infant Death Syndrome of the AAP establishes and updates evidence-based policies. The most recent policy statement was issued in November 2005. (<http://www.aap.org/healthtopics/Sleep.cfm>)
2. Association of SIDS and Infant Mortality Programs: This association of health and human service providers promotes programs of counseling, education, advocacy, and research to ensure a supportive community response for those affected by infant and child death and to reduce the risk of death for children in the future. (<http://www.asip1.org/>)
3. CJ Foundation for SIDS: This national charitable organization funds SIDS research, support services and public awareness programs. (<http://www.cjsids.com>)
4. US Consumer Product Safety Commission: The Commission is charged with protecting the public from unreasonable risks of serious injury or death from more than 15,000 types of consumer products under the agency's jurisdiction. (<http://www.cpsc.gov/about/about.html>)
5. First Candle/SIDS Alliance and the National SIDS and Infant Death Program Support Center: Sample policies and procedures for neonatal intensive care units and well baby nurseries were developed to promote awareness and adoption of safe sleep in accordance with the recommendations of the AAP, the National Institute of Child Health and Human Development, and others. Sample policies and procedures and information about the program's national educational campaign for nurses in neonatal intensive care units and well baby nurseries are on First Candle's Web site. ([www.firstcandle.org/advocacy/model\\_program.html](http://www.firstcandle.org/advocacy/model_program.html))
6. Health Resource and Service Administration: An agency of the US Department of Health and Human Services, it is the primary federal agency for improving access to healthcare services for people who are uninsured, isolated, or medically vulnerable. (<http://www.hrsa.gov/>)
7. March of Dimes: Through research, community services, education, and advocacy, this program address its mission to prevent birth defects, premature birth, and infant mortality. (<http://www.marchofdimes.com/>)
8. National Institute of Child Health and Human Development: Distributes and revises the Back to Sleep campaign materials. The NICHD conducts and supports research on topics related to the health of children, adults, families, and populations. Educational materials on SIDS risk reduction may be obtained, without charge, in both English and Spanish. (<http://www.nichd.nih.gov/health/topics/SIDS.cfm>)