Qualitative Analysis of Beliefs and Perceptions about Sudden Infant Death Syndrome in African-American Mothers: Implications for Safe Sleep Recommendations

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Objective To investigate, by using qualitative methods, perceptions about sudden infant death syndrome (SIDS) in African-American parents and how these influence decisions.

Study design Eighty-three mothers participated in focus groups or individual interviews. Interviews probed reasons for decisions about infant sleep environment and influences affecting these decisions. Data were coded, and themes were developed and revised in an iterative manner as patterns became more apparent.

Results Themes included lack of plausibility, randomness, and vigilance. Many mothers believed that the link between SIDS and sleep position was implausible. Because the cause of SIDS was unknown, they did not understand how certain behaviors could be defined as risk factors. This confusion was reinforced by perceived inconsistency in the recommendations. Most mothers believed that SIDS occurred randomly (“God’s will”) and that the only way to prevent it was vigilance.

Conclusions Many African-American mothers may not understand the connection between SIDS and sleep behaviors or believe that behavior (other than vigilance) cannot affect risk. These beliefs, if acted on, may affect rates of safe sleep practices. Efforts to explain a plausible link between SIDS and safe sleep recommendations and to improve consistency of the message may result in increased adherence to these recommendations. (J Pediatr 2010;157:92-7).

Despite the 50% decline in the incidence of sudden infant death syndrome (SIDS) in the United States since the first American Academy of Pediatrics (AAP) recommendations for infant sleep position in 1992,1 African-American infants remain twice as likely to die from SIDS as Caucasian infants.2 This racial disparity exists across all educational and income categories, and the extent of the racial disparity has increased,3 despite efforts by the Back to Sleep campaign to target African-American families with safe sleep recommendations. These disparities can be partially attributed to behavioral factors. African-American parents place their infants prone for sleep at approximately double the rates of other racial/ethnic groups,4 and the latest (2008) data from the National Infant Sleep Position survey demonstrate that the prevalence of African-American infants placed prone may be increasing.5 African-American infants are also more likely to bedshare6,7 and to experience a bed-sharing death8 than non-African-American infants. Several studies have suggested an increased risk for sudden unexpected infant death when infants bedshare on adult beds, particularly in the presence of parental smoking.9-11 Currently, approximately half of all sudden and unexpected infant deaths in the United States occur when the infant is sharing a sleep surface with someone else,12-14 and the rates of these deaths are increasing.15 Very little is known about how parents perceive SIDS and how these beliefs and perceptions may impact their decisions to adhere to safe infant sleep recommendations. To better understand parental decisions and because of the racial disparity seen in both SIDS rates and SIDS risk reduction behaviors,3,4,6,7,16 we conducted a qualitative study of African-American parents. Few earlier qualitative studies have investigated factors influencing parental decisions about sleep position and bedsharing in low-income, largely African-American families17-20; no studies have included higher income families, and none have studied parental beliefs and perceptions about SIDS.

Methods

We conducted a qualitative study, using both focus group interviews and individual in-depth semi-structured interviews with African-American parents, to examine parental beliefs and perceptions about SIDS. We used 2 different

AAP American Academy of Pediatrics
SES Socioeconomic status
SIDS Sudden infant death syndrome
WIC The Special Supplemental Nutrition Program for Women, Infants, and Children

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We conducted 13 focus groups and 10 individual interviews between July 2006 and December 2008. All participants were mothers. A total of 73 mothers (47 lower SES, 26 upper SES) participated in the focus groups, and 10 mothers (7 lower SES, 3 upper SES) in individual interviews. There were, on average, 4.9 participants (range, 3-7) at each focus group. The mean infant age was 2.6 months (range, 0.5-6.0 months) at the time of the initial quantitative survey and 5.4 months (range, 1.1-9.3 months) at the time of the focus group or individual interview. Other participant characteristics are described in Table II. When demographic characteristics of participants were compared with those of parents who did not participate in focus groups or individual interviews, there were no statistical differences in mean maternal or qualitati
The themes were consistent in all the interviews. These themes are described, with illustrative verbatim comments in accompanying Tables III, IV, and V (available at www.jpeds.com).

Lack of Plausibility (Table III)

Many mothers did not understand the connection between sleep position and SIDS and did not see this link as being a plausible one. Particularly because the cause of SIDS is “when you don’t know why the baby died,” they did not understand how one could say that a particular sleep position can protect against an entity for which the cause is unknown (quotations 1, 2). Furthermore, many mothers described the concept of supine sleeping as the safest position to be counterintuitive. Many mothers perceived prone positioning to be the safest for infants, because they believed it to be the position that is most protective against aspiration and choking when the infant vomits or spits up (quotation 3).

Several mothers did not understand how any risk factors or protective factors could be defined for an entity that is not explained. Therefore, statements from health care professionals, media, or manufacturers that specific behaviors or products could help reduce the risk for SIDS were viewed skeptically. Mothers felt that they needed proof or a guarantee before they would believe that a behavior (eg, supine sleep position) or a commercial product would reduce SIDS risk (quotations 4, 5).

Furthermore, a number of participants believed risk reduction to be an absolute concept: you could either entirely eliminate the risk, or you could not eliminate the risk at all. Most of the mothers were aware of families who had lost an infant to SIDS. Some of these infants were lying supine when found dead. Because of these real-life examples, these mothers were skeptical that sleeping supine would protect their infant from SIDS (quotations 6, 7).

This skepticism was reinforced by the perception that there has been frequent change in the recommendations. Mothers who perceived that the recommendations were always changing were more likely to discount the importance of the recommendations, consider the current advice as a fad, and speculate that the recommendations would likely change again in the near future (quotation 8). This uncertainty was also exacerbated when the behavior of medical and health care professionals was inconsistent with the safe sleep recommendations. Seeing or hearing of a health care professional not following the AAP recommendations sent a clear message to mothers that these recommendations were unimportant (quotations 9, 10).

The 3 major themes about understanding of SIDS were lack of plausibility, randomness, and vigilance. Although qualitative analysis does not allow for quantitative stratification of the themes by SES or by interview format, we found that, with the exception of vigilance (which was a more prominent theme in interviews with mothers of low SES), infant age, maternal marital status, Medicaid status, infant sex, or presence of other children, other parent, or senior caregiver in the home. Furthermore, there were no statistical differences in the 2 groups for pacifier use, breastfeeding, roomsharing without bedsharing, bedsharing, or sleep position.

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re-breathing exhaled carbon dioxide as a potential mechanism for SIDS was explained in several of the focus groups. Mothers believed that to be a plausible explanation for how sleep position and SIDS may be linked (quotations 13).

**Randomness (Table IV)**
Most mothers in this study believed that SIDS occurs randomly and that there was nothing one could do to decrease risk. In contrast, many viewed suffocation as a preventable cause of death (quotations 1–3). Much of this seemed to be derived from the mothers’ belief that, should SIDS occur, it would be “God’s will.” Therefore, most of the mothers believed that their responsibility was to make the best decisions they could for their infant on a day-to-day basis, assuring that the infant’s needs for comfort, longer sleep, and happiness were met (quotations 4, 5).

Most mothers admitted to worrying about the possibility of SIDS, but it was a concern that was most prominent in the first few days of the infant’s life. As mothers became more comfortable with caring for their infants, they became less worried about the possibility of SIDS. Other concerns, such as the infant sleeping better, became more pressing than the concern for SIDS (quotation 6).

**Vigilance (Table V)**
Mothers, particularly those in the lower SES groups, consistently believed that their own vigilance was the most important factor in preventing SIDS. Sleep position, sleep location, and other sleep behaviors were considered irrelevant as long as the parent was next to and closely watching the infant (quotations 1, 2). Indeed, some mothers placed their infant in bed or on a couch next to them in the belief that they could best protect their infant when the infant was near (quotations 3, 4). Some mothers believed that increased parental vigilance was responsible for the decreased rate of SIDS in other racial/ethnic groups and suspected that lack of vigilance was largely responsible for the racial disparity in SIDS (quotation 5).

**Discussion**
Although a few earlier studies have used qualitative methods to understand motivations behind parental decisions for safe infant sleep practices, we have investigated parental beliefs and perceptions about SIDS itself. Our findings that the African-American mothers in our cohort perceive the link between risk factors and SIDS to be implausible, SIDS to be a random, unpreventable occurrence, and parental vigilance to be the key to SIDS prevention build on the findings of earlier studies. Our findings also appear to indicate that these beliefs extend to families of higher SES. Because the racial disparity in SIDS is present at all socioeconomic and educational levels, these findings may help explain why the Back to Sleep campaign has been less successful in African-American families and may provide a framework for more effectively eliciting behavior change.

Responses from our interviews suggest that the Back to Sleep campaign’s difficulty in gaining acceptance in African-American parents has been exacerbated by the inconsistencies in the safe sleep recommendations. When parents observe health care providers placing infants prone or perceive that their health care provider does not endorse safe sleep recommendations, the importance of adhering to these recommendations is greatly diminished. In addition, the changing emphasis in the AAP recommendations on the importance of supine sleeping as the preferred position has inadvertently given the impression of an inconsistent message and has confused parents. Finally, many parents and health care providers continue to believe that infants are more likely to aspirate when they are lying supine, despite evidence to the contrary, and therefore are skeptical that the current recommendation for back positioning will keep infants safe. This concern has been noted to be more pressing for African-American parents and caregivers. Education for caregivers must go beyond distribution of the guidelines. Our results and those of other studies suggest that parents would welcome detailed explanations for why supine position is safest and addressing concerns about aspiration. It is possible that parents would be more likely to view safe sleep recommendations as important and follow them if their questions and concerns about the recommendations were addressed. Otherwise, it seems more likely that immediate needs of the infant and family, such as the infant’s comfort level or the parent’s need to sleep, will take priority over SIDS risk reduction.

SIDS is defined as the death of an infant for which no cause is found. Our study participants were well aware of this definition and understood that following safe sleep guidelines would not guarantee that SIDS would not occur. Unfortunately, when parents interpret this as meaning that their infant’s SIDS risk will not be influenced by their decisions and behaviors about where and how their infant sleeps, they may be less likely to change sleep behavior to reduce SIDS risk. Indeed, the concept of risk reduction was not compelling for many parents; they did not see the usefulness in changing sleep behavior to reduce SIDS risk unless they could be assured that this change would provide a 100% guarantee that SIDS would not occur.

In contrast, suffocation was viewed as a plausible and preventable cause of sudden infant death, and parents in our cohort generally believed that they could prevent infant suffocation by actions such as removing blankets or pillows from their infants’ cribs. Some parents stated that they would have been more likely to place their infants supine if they had been told that it could prevent rebreathing or suffocation. Suffocation and asphyxia are causes of sudden, sleep-related infant deaths that are preventable. As the quality of death scene investigations has improved and become more consistent, there has been a diagnostic shift, such that many deaths that would have been coded as SIDS are now being coded as suffocation or asphyxia; the rate of accidental suffocation and strangulation in bed for infants has quadrupled in recent years. This increase in accidental deaths may...
have implications for public health interventions; an emphasis on the preventability of these types of deaths may be more likely to result in behavior changes that could decrease the rates of all sudden, sleep-related infant deaths, including SIDS.

It is concerning that some parents, particularly those of low SES, in an effort to maintain constant vigilance over their infants, may inadvertently place the infant at increased risk for SIDS and other sleep-related deaths. Many parents in our study reported laying the infant for sleep in the bed or on the couch with them to watch the infant closely. This is consistent with the findings of other qualitative studies that have found that many parents will bedshare in the belief that this is the best way to keep their infant safe. It is important that parents understand the risk of these practices and are given safe alternatives, such as roomsharing without bedsharing, that allow for parental vigilance without increasing risk to the infant.

This study population was limited to African-American mothers in the Washington, DC, area. In addition, although qualitative studies can provide a wide range of opinions, they cannot be used to define the prevalence of any particular attitude or opinion. Therefore, these results may not be generalizable to other racial/ethnic groups or other localities. However, our findings are largely consistent with other qualitative studies of largely African-American populations and one study with African-American and Caucasian participants, suggesting that many of the perceptions about sleep position and sleep location are widespread and continue to be held 15 years after the supine sleep position was first recommended. However, there may be cultural distinctions in viewpoints and concerns. Therefore, it will be important to expand this study to other racial/ethnic groups and geographic areas to determine how prevalent these beliefs are in the society as a whole.

If Back to Sleep and other safe sleep recommendations are to be embraced by more African-American parents, a plausible link between the recommendations and SIDS or other sudden sleep-related deaths needs to be more clearly established for parents, so that parents believe that their actions can be effective in reducing the risk of these deaths. Additional guidance should be provided about roomsharing without bedsharing and other alternatives that will allow parents to maintain vigilance without endangering the infant. Finally, if parents are to perceive the messages as being credible and important, there needs to be consistency in the safe sleep messages that are provided by health care professionals and other sources of information for parents.


References


Table I. Questions about sudden infant death syndrome beliefs used in focus groups and individual in-depth interviews

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<th>Question</th>
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<td>1. Have you ever heard of SIDS?</td>
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<td>2. What do you think SIDS is?</td>
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<td>3. When did you first hear about SIDS?</td>
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<td>4. Did you know that the risk of SIDS is higher in the African-American community than any other community?</td>
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<td>5. Do you worry about SIDS happening to your baby?</td>
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<td>6. Do you know anyone who has had a baby die suddenly?</td>
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<td>7. What do you think causes SIDS?</td>
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<td>8. Do you think that you can do anything to try to keep SIDS from happening? If so, what? If not, why not?</td>
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<td>9. Do any of the SIDS recommendations have an impact on how you care for your baby?</td>
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Table II. Lack of plausibility

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<td>1. “But if it’s no known reason, how can you say if I put my baby on his back that it will reduce the chance of SIDS? You know what I mean?”</td>
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<td>2. “If they don’t know why the babies died, why does it matter which way you laid your baby?”</td>
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<td>3. “Because he could choke on his back... They could choke on their tongue, they could swallow their slobber, they’re on their back. He could choke off his own spit-up, you know... to make more sense that if they are on their stomach.”</td>
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<td>4. “How are you going to say (a product) guard(s) against it when you don’t know why it happens? So, yeah I don’t believe that.”</td>
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<td>5. “(For me to use the back position,) I need a guarantee, 100%. The whole thing, not half, the whole thing.”</td>
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<td>6. “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.”</td>
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<td>7. “If I know 100% all the children never died from SIDS when they laid on their back, that will convince me, but if you have one child or like 10% of the kids still on their back are not surviving on their back now, something is wrong or it’s something else missing.”</td>
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<td>8. “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.’’</td>
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<td>9. “Each pregnancy they always stress (that babies should sleep) on the back. But this last pregnancy, the nurse brought the baby back to my room, he was on his stomach...I thought it was odd that the nurse had placed the baby on his stomach... If you’re stressing SIDS so much, why would you place him on his stomach?”</td>
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<td>10. “And my pediatrician first told me she kept her daughter on her stomach, so...There’s people who tell people to do these things, but they do the opposite.”</td>
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<td>11. “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.”</td>
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<td>12. “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.”</td>
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<td>13. “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.”</td>
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Table III. Randomness

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<td>1. “I believe that it’s just something that just happens. You don’t know when... or if it’s going to happen to you... I don’t believe that there is anything that probably I can do to avoid it.”</td>
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<td>2. “It’s just like if it’s your time to go, you know what I’m saying? It’s nothing you can do, you know. So my other kids slept on their stomach, you know, and I never heard anything about SIDS then, and now it’s like, what’s the problem?”</td>
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<td>3. “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.”</td>
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<td>4. “I don’t think anything’s wrong with sleeping on the stomach...If anything was to happen to my baby, I would just feel like, because of my faith in God, I would just feel like, “Ok, Lord, this is something that you allowed, so this is something that I have to accept.” And I don’t think I would go through, ‘Well, I should have done this,’ or ‘I shouldn’t have.’ I can’t live my life that way in terms of ‘I should have done it this way, I should have done it that way.’ I just believe that...if it did happen, it was just time, it was what was supposed to happen to me in my life.”</td>
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<td>5. “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 doing with my baby 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.”</td>
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<td>6. “At first when they are newborns, don’t get me wrong, I be scared to death... I put him right on the back like they tell you to do, but then after a while, once I get comfortable with the child, and real comfortable about him being home and me being adjusted to him and stuff like that, then I’ll start doing my own little thing... I go by the rules at first, but then once I get back into the midst of caring for a child, then I, you know, like my son he sleeps on his stomach now. And... he sleeps real good on his stomach.”</td>
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Table V. Vigilance

1. “That goes back to watching. Basically, to prevent SIDS just keep an eye out, you know. It all falls back to that, definitely… You can’t just expect that they’re not going to throw up, and if they’re on the back, they might choke; if they’re on the stomach, they might choke… Basically, SIDS is, you know, to prevent SIDS, whatever it is, just keep an eye watch on, you know, pray, and hope for the best for your baby.”

2. “And, you know, also a lot of it deals with experience. I’m experienced (and know) that laying my daughter on her stomach is best. You know, I’ve kept careful watch over her and I didn’t just haphazardly let her just sleep on her stomach. No, I was monitoring her constantly, and it takes that.”

3. “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.”

4. “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.”

5. “I still don’t believe that being on their back is really changing anything. Maybe (parents from other racial/ethnic groups) are paying more attention to their child. Maybe they are seeing how their baby is reacting when they do this and when they do that, how they lay them… Like, I’ve seen friends that just lay their babies on the stomach and turn their head to the side, instead of monitoring their baby and making sure that the baby is comfortable like that… They leave them like that.”

Acknowledgments

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