Mothers' Decision Making Concerning Safe Sleep for Preterm Infants

What Are the Influencing Factors?

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ABSTRACT

Background: Parental decisions regarding infant sleep practices vary widely, resulting in a lack of adherence to the American Academy of Pediatrics safe sleep recommendations (SSR) and consequently an increased risk of sudden infant death syndrome (SIDS). Preterm infants are among those at a highest risk for SIDS, yet few studies focus on parental decision-making surrounding sleep practices for preterm infants.

Purpose: The purpose of this study was to identify factors influencing decisions concerning infant sleep practices of mothers of preterm infants.

Methods: This study used a mixed-methods design. Recruitment was through social media messaging by 2 parent support organizations. An online survey was used to assess factors influencing mothers' decisions regarding sleep practices for preterm infants.

Findings/Results: Survey participants (n = 98) were from across the United States. Mothers of preterm infants (mean gestational age at birth = 29.42 weeks) most often reported positioning infants on their back to sleep (92.3%) and a low (15.4%) use of a pacifier at sleep time. Three themes emerged for the decisions made: adherence to SSR; nonadherence to SSR; and infant-guided decisions. Regardless of the decision, mothers indicated that anxiety over the infant's well-being resulted in a need for sleep practices that facilitated close monitoring of the infant.

Implications for Practice and Research: The findings of this study indicate the need for understanding the underlying anxiety preventing mothers from adhering to SSR despite knowing them, along with tailoring infant sleep messaging and education to improve safety of sleep practices for preterm infants. Research is needed to examine decision making in more diverse populations.

Key Words: decision making, infant safe sleep, preterm infant sleep, sudden infant death syndrome, sudden unexpected infant death

BACKGROUND AND SIGNIFICANCE

Infant mortality is a national health concern, with more than 3600 deaths in 2018 of infants younger than 1 year from sudden infant death syndrome (SIDS) and other sleep-related causes.[1] SIDS, defined as the sudden death of an infant that remains unexplained after examination, review of the death scene, and autopsy,[2] is subsumed as one component of a broader classification of sudden unexpected infant death (SUID).[3] SUID is a sudden unexpected death that can be attributed to factors such as suffocation or strangulation from entrapment during sleep.[3] While both are used professionally and in literature, SIDS was used in this study as it is the term most familiar to parents. SIDS posits a health concern for all infants but particularly for preterm infants because as gestational age decreases, the risk for SIDS increases.[4-6] One study found that infants born between 24 and 27 weeks of gestation have a more than 4 times higher death rate from SIDS (2.68 per 1000 live births) than term infants (0.51 per 1000 live births).[6] These statistics reflect the biological and social vulnerability of the preterm infant, as well as the potential for an increased number of coexisting risk factors, including modifiable risks such as a lack of prenatal care, smoking, and nonadherence to sleep recommendations that have shown to reduce risk.[6]

Infant death rates declined significantly over a span of 9 years following the 1992 American

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Ethical approval was provided by the institutional review board of Case Western Reserve University in advance of implementation. Submission of survey served as informed consent.

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Academy of Pediatrics (AAP) recommendation of a supine sleep position and initiation of the 1994 national Back to Sleep campaign; however, the incidence of sleep-related deaths has not continued to decline.[3] The revised 2016 AAP safe sleep recommendations (SSR) incorporated growing evidence linking modifiable factors in the sleep environment that can decrease SIDS and SUID risks.[7] The recommendations include 3 levels (levels A, B, and C) assigned using the Strength of Recommendation Taxonomy (SORT) based on quality and strength of evidence. Level A modifiable recommendations have the strongest-quality patient-oriented evidence.[8] Six of the level A modifiable recommendations were selected for this study based on the use in safe sleep education (Table 1). Although the evidence to support the recommendations continues to grow, parental practices regarding infant sleep vary widely and reflect a lack of adherence to the AAP SSR.[9-11] This lack of adherence to SSR leads to an unintended consequence of increasing risk for infant death during sleep.

Preterm infants are the most vulnerable infants and among those at the greatest risk for SIDS, but few studies in the literature examine maternal decision-making for sleep practices for preterm infants. A gap exists in the literature with a lack of studies that focus on factors influencing decisions made by mothers of preterm infants concerning sleep practices. The primary objective of this study was to identify factors influencing mothers' decisions regarding sleep practices for their preterm infant.

LITERATURE REVIEW

Factors Related to Adherence to SIDS SSR

Beliefs and attitudes of parents concerning specific recommendations, knowledge of the SSR, and advice from family and healthcare professionals are 3 main factors that have been identified as contributing to parents' adherence or nonadherence to SSR.[12-16] Perception of infant comfort, safety, convenience for breastfeeding, and quality of caregiver sleep are consistently reported as reasons for decisions leading to nonadherence to SSR,[17-20] as well as fear of the infant choking[21-23] and positional plagiocephaly.[23,24] Martiniuk et al[24] found most mothers have heard of flat head (positional plagiocephaly) and the importance of changing the infants head position to prevent it but reported being confused because the information conflicts with the supine sleep position for SSR. Studies have found that parents feel knowledgeable concerning safe sleep practices,[25] and parents of preterm infants reported a statistically significant improvement in knowledge of SSR following participation in an educational program before discharge.[26] Surprisingly, this improvement in knowledge was not reflected in the parents' adherence to SSR 4 weeks after discharge.[26]

Sleep behaviors modeled during hospitalization influence sleep practices, and although nurses provide advice and model care practices at several different times during hospitalization of preterm infants, there are noted inconsistencies in practice.[27,28] The transition of the infant to a supine sleep position does not always happen soon enough prior to discharge for the infant to become accustomed to sleeping on their back.[28] Barsman et al[27] noted that only 60% of nurses transitioned infants to a supine sleep position prior to discharge, which adversely impacts the education provided to parents on safe sleep practices.

Disparities in race, ethnicity, socioeconomic status, and level of education were also noted in several studies on the risk of SIDS.[4,9,19] Infants of African American women, who have higher rates of preterm birth than other races,[5] are less likely to be placed on their back to sleep[29] and found to be 2 to 3 times more likely to die of SIDS or accidental suffocation during sleep than White infants.[1,6,16] Women with a lower education level are less likely to position infants on their back to sleep[9,29] and have a higher rate of infant death from SIDS.[4]

Several studies have found that sleep practices changed over time after discharge with an increase in bed-sharing and nonsupine sleep position.[10,26,30] Parental decisions for sleep practices for term and preterm infants, including multiples, resulted in a lack of adherence to the AAP sleep recommendations and unintentional increased risk for SIDS.[5,26,30,31]

Decision making has been widely studied across multiple disciplines to better understand its nature.

What This Study Adds

- Decisions related to sleep practices for preterm infants lead to adherence and nonadherence of SSR.
- Parents of preterm infants have a need to become the monitor for their infant during sleep.
- Emotions and stress of caring for a preterm infant after discharge from the NICU influence decisions for preterm infant sleep practices at home.

TABLE 1. Level A Modifiable Factors in the Sleep Environment

Back positioning
Use of firm sleep surface
Room-sharing without bed-sharing
Avoidance of soft bedding and overheating
Breastfeeding
Use of pacifier at sleep

[a]Level A recommendations have good-quality patient-oriented evidence, with levels assigned on the basis of the Strength of Recommendation Taxonomy (SORT).[7]

Lerner et al[32] reported on the powerful and pervasive influence of emotion on decision making and found that decisions are made on the basis of emotion, judgment, or a choice at hand. Maternal decisions regarding infant sleep practices have been found to be related to previous experience, as well as social and cultural factors.[28] The perplexing and challenging phenomenon of decision making is an important underpinning to improving adherence to SSR.

The Health Belief Model (HBM) was the conceptual framework used for this study. Developed to explain adherence to medical regimens, the HBM posits that personal health behavior is influenced by specific health beliefs about vulnerability and perceived threat. It has been applied to many types of health behavior and is often used as the theoretical basis to design interventions to influence change and adherence.[33,34]

The research questions of this study are as follows: (1) What are the infant and mother sleep practices reported by mothers of preterm infants concerning the AAP SSR? (2) What factors influence decisions of mothers of a preterm infant concerning their preterm infant's sleep environment (sleep location, sleep position, sleep environment including items in the crib) and pacifier use at sleep time? (3) What are the differences between sleep practices reported by mothers of preterm infants 1 year or younger and mothers of infants older than 1 year?

The overall long-term goal of this study is to improve safety during sleep for preterm infants through the identification of approaches that will provide guidance in tailoring safe sleep messaging and education and to increase adherence to the AAP SSR. The importance of this study is to fill a gap in the literature concerning factors influencing maternal decision-making related to sleep practices of preterm infants and risk reduction of SIDS.

METHODS

Design

This was a descriptive, cross-sectional, mixed-methods study that examined decision making of mothers of preterm infants regarding sleep practices and their perceived risk for SIDS, strangulation, and suffocation through completion of an online survey.

Sample/Setting

A convenience sample of mothers (n = 98) caring for their preterm infant at home was recruited for this study. Inclusion criteria included mothers caring for their preterm infant at home 1 month or more after discharge from the birth hospitalization, ability to read English, and Internet access. Exclusion from the study included mothers caring for a preterm infant requiring use of a home monitor, oxygen, or home ventilator.

Measures

The online Qualtrics Preterm Infant Sleep Survey used in this study was adapted from a survey tool used in 3 previous studies evaluating sleep care practices of preterm and term infants at pre- and postdischarge.[9,23,28] The 49-item survey includes maternal and preterm infant demographics, assessed infant and mother sleep practices, decision making regarding sleep practices, and perception of risk for SIDS. The survey contained mainly multiple-choice questions with skip logic to ease participant burden. Six open-ended questions allowed for narrative responses regarding important decisions made along with reasons why decisions were made concerning their infant's sleep practices.

Procedure

This study was approved by the institutional review board of Case Western Reserve University. Recruitment took place over a 2-month period. The link to the Qualtrics survey was posted on 2 Web sites of organizations providing support for parents of preterm infants, Graham's Foundation (https://grahamsfoundation.org/) and Project NICU (previously known as Project Preemie) (https://www.projectnicu.com/). Periodic messaging posts to the organizations' social media network Facebook page, Instagram, and Twitter accounts were sent over the 2-month period. The online survey started with a description of the study with inclusion and exclusion criteria, acknowledging that caring for a preterm infant can be challenging and that we wanted to better understand sleep practices for preterm infants' home at least 1 month from the initial neonatal intensive care unit (NICU) hospitalization. Submitting a completed survey served as consent.

Data Analysis

Data were downloaded from Qualtrics and analyzed using IBM SPSS version 27. The demographic variables and quantitative survey items were analyzed with descriptive statistics and frequencies including mean, standard deviation, range, and percentages. A chi-square test of independence was performed to examine the relationship between maternal demographics and the 2 different age groups. Maternal demographic variables included race, ethnicity, education level, marital status, geographic location, and work status outside the home. An independent-samples *t* test was used to test the differences between infant variables of gestational age at birth, birth weight, age in months at the time of survey, and length of hospital stay by the 2 different age groups. A chi-square test was also conducted to determine the relationship of 6 safe sleep variables: back to sleep position; sleeps in own separate bed; sleeps in parent room; no loose items in bed; feeding human milk exclusively; and use of pacifier at time of sleep

between age groups of 1 year or younger and older than 1 year. We used an α level of .05 for all statistical tests. Content analysis (n = 98) was used to evaluate self-reported decisions and factors influencing the reason for decisions regarding infant sleep practice. The responses to each of the open-ended questions (n = 98) were reviewed independently by 2 of the authors, and initial codes were identified. Themes and subthemes were developed from the initial identified codes, and comparison was done between responses for infants 1 year or younger and infants older than 1 year. Narratives from the open-ended questions by mothers with infants older than 1 year were reviewed to determine the time frame for the reported sleep practices.

RESULTS

A total of 98 participants submitted completed surveys (see Survey, Supplemental Digital Content 1, available at: http://links.lww.com/ANC/A123, which includes survey questions and demographics). The sample (mean age of 33 years) consisted primarily of White, well-educated women. Participant demographics for the entire sample, plus groups separated by ages of 1 year or younger and older than1 year, are found in Table 2. The organizations' Web sites and use of social media provided opportunity to reach mothers from various regions across the United States: Midwest (25.2%), Northeast (17%), Southeast (17%), Southwest (7%), and West (29%), as well as one mother in Ireland, but found no statistical difference between geographic location and age groups ($\chi^2_{4,98} = 4.7$, $P = .315$). No statistical significance was found between the age groups for race ($\chi^2_{5,98} = 4.1$, $P = .538$), ethnicity ($\chi^2_{1,98} = 1.1$, $P = .307$), education ($\chi^2_{4,98} = 2.8$, $P = .598$), and working outside the home ($\chi^2_{3,98} = 7.5$, $P = .057$). Although the category for working outside the home was not statistically significant ($P < .001$), the number of mothers reporting not working outside the home by itself has statistical significance. Infant demographics are listed in Table 3. Sixty-four percent of the sample had infants older than 1 year at the time of the survey. The independent-samples t test conducted found no statistical significance between the age groups and infant demographics for weeks of gestation at birth, birth weight, and length of hospital stay. Statistical significance was found in age of infants at time of the survey for infants 1 year or younger ($M = 7.9$, SD = 3.2) compared with infants older than 1 year ($M = 43.3$, SD = 3.9), $t_{7.2} = 63.4$, $P < .000$, and the time home since initial NICU hospitalization for infants 1 year or younger ($M = 5.9$, SD = 3.2) compared with infants older than 1 year ($M = 39.9$, SD = 38.8), $t_{6.9} = 63.5$, $P < .000$. Six SSR used in this study to determine reported mother and infant sleep practices are detailed in Table 4. Statistical significance was found in sleep practices for infant sleeping in the parent room ($\chi^2_{1,98} = 5.8$, $P = .016$), infant sleeping in their own room ($\chi^2_{1,98} = 5.0$, $P = .025$), infant sleeping in the parents' bed ($\chi^2_{1,98} = 3.9$, $P = .049$), blanket or quilt in bed ($\chi^2_{1,98} = 4.5$, $P = .034$), pillow in bed ($\chi^2_{1,98} = 4.5$, $P = .034$), and no items in bed ($\chi^2_{1,98} = 4.6$, $P = .032$). The qualitative data were reviewed for similarities and differences in reports of mothers in the 2 age groups. Similarities noted in responses determined that reports from mothers of infants older than 1 year reflected their sleep practices at the time when the infant first came home:

> For the first 6 months our daughter slept in a bassinet by our bed. (27 weeks, current age 2 years)

> Keeping him in our room as long as possible, we wanted him as close as possible to keep him safe. (30 weeks, current age 8 months)

Infant Sleep Practices

An unexpected finding in this study was the number of participants with infants older than 1 year. Of the 98 participants, 64.2% were mothers of a preterm infant who at the time of the survey ranged in age from 2 to 18 years. The intended focus for infant age for this study was preterm infants younger than 1 year since this is the time of greatest risk for SIDS. Consequently, the quantitative data concerning sleep practices were divided into 2 age groups to include the responses of mothers of infants 1 year or younger (n = 35) and responses of mothers of infants older than 1 year (n = 63). Table 4 describes the sleep practices reported by mothers for their infants 1 year or younger and infants older than 1 year.

For both age groups, a back sleep position had the highest adherence for infants 1 year or younger (94.3%) and infants older than 1 year (81%), with pacifier use at the time of sleep had the lowest (22.9%) for infants 1 year or younger and 20.6% for infants older than 1 year. The mother's perceived level of risk of SIDS for her infant on a scale of 1 to 5 is average (23.1%), with none indicated very high risk for infants younger than 6 months.

Factors Influencing Decisions

Three major themes emerged for the types of decisions that were made: decisions reflecting (1) adherence to SSR; (2) nonadherence to SSR; and (3) infant-guided decisions (Table 5). Factors for making the decisions were then aligned with the type of decision. Decisions guided by infant behaviors included subthemes of sleep regulation and feeding schedules. Of interest were the subthemes of bed, room-sharing, and sleep position. These subthemes were reflected in both adherent (room-sharing, not bed-sharing) and nonadherent decisions

TABLE 2. Participant Demographics Comparison of Mothers With Infants 1 Year or Younger and Older Than 1 Year

Participant Characteristics Maternal	1 y or Younger (N = 35), n (%)	Older Than 1 y (N = 63), n (%)	Total (N = 98), n (%)	P[a]
Race				.538
White	31 (91.2)	49 (77.8)	80 (81.5)	
Black	0	2 (3.2)	2 (2.1)	
American Indian/Alaska Native	0	1 (1.6)	1 (1.0)	
Asian	1 (2.9)	2 (3.2)	4 (4.1)	
>1 race	3 (8.5)	6 (9.5)	8 (8.2)	
Other	0	3 (4.8)	3 (3.1)	
Ethnicity				.307
Hispanic/Latino	3 (8.6)	10 (15.9)	13 (13.3)	
Not Hispanic/Latino	32 (91.4)	53 (84.1)	85 (86.7)	
Education				.594
High school/GED	1 (2.9)	6 (9.5)	7 (7.2)	
Associate	3 (8.6)	9 (14.3)	12 (12.2)	
Baccalaureate	12 (34.3)	21 (33.3)	33 (33.7)	
Graduate school	13 (37.1)	17 (27.0)	30 (30.6)	
Some college (no degree)	6 (17.1)	10 (15.9)	16 (16.3)	
Marital status				.754
Married	31 (88.6)	55 (87.3)	86 (87.8)	
Single	2 (5.7)	3 (4.8)	5 (5.1)	
Divorced	0	2 (3.2)	2 (2.1)	
Live in partner	2 (5.7)	3 (4.8)	5 (5.1)	
Geographic location				.315
Midwest	11 (31.4)	14 (22.2)	25 (25.5)	
Northeast	4 (11.4)	13 (20.6)	17 (17.3)	
Southeast	2 (5.7)	11 (17.5)	13 (13.3)	
Southwest	2 (5.7)	5 (7.9)	7 (7.2)	
West	12 (34.3)	17 (27.0)	29 (29.6)	
Other (Ireland)	1 (2.9)	0	1 (1.0)	
Missing	3 (8.6)	3 (4.8)	6 (6.1)	
Working outside the home				.057
<20 h/wk	4 (11.4)	5 (7.9)	9 (9.2)	
21-35 h/wk	13 (37.1)	36 (57.1)	49 (50)	
≥36 h/wk	0	4 (6.3)	4 (4.1)	
Not working outside the home[b]	**18[c] (51.4)**	**18[c] (28.6)**	36 (36.7)	

[a]Pearson's chi-square test. P values reflect results of X2 tests testing categorical differences between demographics and age groups.
[b]Not working outside of the home within group.
[c]Bold indicates statistically significant P value.

(co-sleeping, use of monitors, and elevation of mattress). The factors for nonadherent and adherent decisions indicated a fear of something happening to the infant if they were not vigilant in monitoring the infant during sleep. An overriding impression was the parent's need to become the infant's monitor, replacing monitors that had been removed just before discharge from the NICU. Similarities in words describing reasons for decisions were noted between the 2 age groups, with the most frequent being "monitor," "observe," and "keeping close" found in responses of 20% of mothers with infants 1 year or younger and among 19% of mothers with infants older than 1 year. Five percent reported purchasing a home monitor because of feeling anxious, fearful, or worried.

TABLE 3. Infant Characteristic Comparison of Ages 1 Year or Younger and Older Than 1 Year (N = 98)

Infant Characteristics	1 y or Younger (N = 35), n (%)	Older Than 1 y (N = 63), n (%)	Total (N = 98), n (%)	P[a]
Gestational age at birth, wk				
Mean (SD)	30.2 (3.9)	29.0 (3.8)	29.4 (3.8)	.150
Min-Max	22-36	23-34	22-36	
Birth weight, g				
Mean (SD)	1532.5 (628.9)	1309.4 (595.1)	1389.1 (613.6)	.085
Min-Max	539-2835	482-2608	482-2835	
Hospital length of stay, wk				
Mean (SD)	8.1 (6.9)	10.3 (8.9)	9.4 (8.4)	.341
Min-Max	0.5-30	0.1-56	0.1-56	
Time home since discharge, mo				
Mean (SD)	5.9 (3.2)	39.9 (38.8)	36.6 (64.7)	**<.001**
Min-Max	1.0-11.0	21-222	1.0-222	
Age at time of survey, mo				
Mean (SD)	7.9 (3.2)	43.3 (38.9)	23.1 (37.2)	**<.001**
Min-Max	1.5-12.0	13-222	1.5-222	

[a]*P values reflect results of t tests to determine statistical differences between the means of 2 age groups.* ***Bold*** *indicates a statistically significant P value.*

Decisions Reflecting Adherence

More than 90% of parents reported putting the infant on their back to sleep; however, few reported that as being the most important decision and when they did, they indicated that it was because they knew it was a component of safe sleep.

The decision to have the infant sleep in their room (own sleeping space) was based on the parents' need for closeness to be aware of the infant's needs, as well as to improve their own sleep. One mother who identified keeping the infant in the parents' room as the most important decision said, "Looking back it was mainly out of fear. It was a difficult transition to not have monitors constantly showing us he was OK" (31 weeks, current age 19 months).

Several reported having the infant sleep in a bassinet, close to their bed, for up to 8 months: "We were uncomfortable having her in another room and could tend to her needs better by our bed" (27 weeks, current age 12 months). Another mother stated, "We chose a bassinet in our room to be close but avoid co-sleeping" (31 weeks, current age 10 months).

Decisions Reflecting Nonadherence

In contrast, 12.2% of the mothers identified co-sleeping (bed-sharing) as their most important decision, which reflects 15.8% of mothers with infants older than 1 year compared with 5.7% of mothers with infants 1 year or younger. It was clear that parents knew that co-sleeping was not safe but concerns for the infant's well-being, as well as the perception that the infant would sleep better, overcame that knowledge.

> Although the risk was high, I opted to have her sleep with me so I could monitor her breathing as she did not come home with any O_2 or monitoring. She had only been off O_2 a few days before coming home and it was my biggest concern. (24 weeks, current age 7 years)

Others mentioned using co-sleepers but did not indicate if they were in or attached to the bed, neither of which are endorsed by the AAP SSR.

Several mothers reported their most important decision as having the infant sleep on an incline because the infant had reflux in the hospital. Another decision that reflected nonadherence to SSR was the use of consumer monitors, either under-the-mattress movement sensor pads or using pulse oximetry that have been marketed to "prevent SIDS"; one mother reported using one until the infant was 18 months old. These monitors were used for reassurance that the infant was OK and to help parents with their own sleep: "When he was initially discharged someone (myself or my husband) would stay up with him to monitor him while he slept. Once we could not physically take being up that much, we purchased a monitor" (31 weeks, current age 19 months).

Decisions Reflecting Infant-Guided Behavior

Some of the infant-guided decisions directing sleep practices reflected the wish to have the infants regulate their own sleep and feeding schedules. One mother stated, "Her sleep in the NICU was constantly interrupted by alarms and lights so it was

TABLE 4. Sleep Practices Comparison of Infants 1 Year or Younger and Infants Older Than 1 Year[a]

Sleep Practice	1 y or Younger (N = 35),[b] n (%)	Older Than 1 y (N = 63),[b] n (%)	P[c]
Position (at time of sleep)			
Back	*33 (94.3)*	*51 (81.0)*	*.07*
Side	5 (14.3)	9 (14.3)	1.0
Stomach	3 (8.6)	8 (12.7)	.53
Room (sleeps most often)			
Parent room	*18 (51.4)*	*17 (27.0)*	***<.001***
Own room	**14 (40.0)**	**42 (66.7)**	**<.001**
Sibling room	2 (5.7)	4 (6.3)	.90
Bed (infant sleeps in)			
Own separate bed	*29 (82.9)*	*42 (59.2)*	*.09*
My bed	2 (5.7)	12 (20.6)	**<.001**
Part time in own bed/part time in my bed	4 (11.4)	8 (12.7)	.84
Items in bed (Yes)			
Blanket or quilt	**8 (22.9)**	**35 (55.6)**	**<.001**
Pillow	**2 (5.7)**	**14 (22.2)**	**<.001**
Toys	3 (8.6)	8 (12.7)	.53
Crib bumpers	3 (8.6)	4 (6.3)	.68
None of these items in bed	*24 (68.6)*	*29 (46.0)*	**<.001**
Feeding			
Exclusively human milk	*13 (37.1)*	*12 (19.0)*	.14
Exclusively formula	14 (40.0)	20 (31.7)	*.25*
Combination of human milk/formula	23 (36.5)	23 (31.7)	.09
Pacifier (at sleep)			
Always	*8 (22.9)*	*13 (20.6)*	.79
Most of the time	4 (11.4)	7 (11.1)	.38
Sometimes	11 (31.4)	12 (19.0)	.31
Never	12 (34.3)	30 (47.6)	.31

[a] *American Academy of Pediatrics safe sleep recommendations in* italics.
[b] *Option for multiple answers to questions so total does not = N.*
[c] *Pearson's chi-square test. P values reflect results of χ^2 tests, which test differences between 6 sleep practices and age groups.* **Bold** *indicates statistically significant P values.*

difficult to establish a normal "schedule" … in the time we've been home we've allowed her to regulate her own sleeping patterns…" (26 weeks, current age 12 months).

Mothers were asked whether there was anything they wanted to tell us about sleep practices and answered with responses consistent with change over time; "When we first arrived home, we were very strict on the rules given to us regarding sleep practices. Over time, we had to adapt those rules to fit our family, while keeping safety in mind" (28 weeks, current age 2 years 4 months). One mother recommended that healthcare providers prepare parents beyond the immediate posthospitalization period:

> There is SO much guidance on what to do right away when babies come home from the hospital, but no guidance on when to relax a little. I was paranoid about introducing a pillow at 2 years old…. I think in the push to educate parents of newborns, the other side of that is neglected—when is it appropriate to introduce those items to toddlers. When does the risk window close? (26 weeks, current age 4 years)

DISCUSSION

While several studies have described the implementation of the SSR for term[9,30] and preterm infants,[26] as well as other high-risk populations of African

TABLE 5. Important Sleep Decisions and Decision Factors

Theme	Most Important Decision, Quote	Factors Influencing Decision, Quote
Adherence to SSR		
Bed	*He sleeps in a bassinet in my room.* (22 wk, current age 12 mo) *Giving him his own sleeping space.* (29 wk, current age 10 mo)	*Because he went from constantly being monitored by machines to not having machines, I wanted to make sure he was close by so I can monitor him* *It helped my anxiety to know he was safely tucked away in his own sleeping space.*
Room	*He slept in a bassinet in our room for the first 7 mo he was home.* (33 wk, current age 9 mo) *Co-sleeper beside our bed.* (23 wk, current age 19 mo) *We decided to have our baby sleep next to our bed.* (30 wk, current age 15 mo)	*Because it felt safer for both of us.* *I wanted to be able to maximize our sleep and the babies sleep.* *We decided to have our baby sleep next to our bed. We needed to be able to hear and care for him whenever he needed us.*
Position	*Always back to sleep and no blankets … baby is alone … no toys.* (25 wk, current age 12 mo) *Safety—not in our bed and on his back, swaddled.* (28 wk, current age 16 mo)	*Through the videos our NICU had us watch before discharge and the fear of SIDS.* *It seemed like the safest option.*
Nonadherence to SSR		
Bed/Co-sleeping	*Co-sleep.* (29 wk, current age 3 y 1 mo) *Co-sleeping.* (24 wk, current age 7 y) *Co-sleeping.* (36 wk, current age 3 mo)	*At first I was scared to put him down and definitely couldn't leave him in another room. Then he wouldn't sleep in his crib so we still sleep together.* *Although the risk was high, I opted to have her sleep with me so I could monitor her breathing as she did not come home with any O_2 or monitoring….* *I made this decision, as it made me feel closer to my baby and much calmer when sleeping myself. Co-sleeping also settled my baby much better; he sleeps much better being next to me….*
Room	*Moved her to her own room quickly.* (27 wk, current age 12 mo)	*She was a light sleeper and would wake up when we were getting ready for bed, then we would be awake all night.*
Elevation of mattress	*Sleeping in an elevated position, even though that's not recommended.* (36 wk, current age 3 y) *Sleeping inclined. To make him comfortable to be able to rest.* (25 wk, current age 1 y 11 mo)	*She had terrible reflux and it affected her ability to feed, which we were concerned about because she was preterm.* *He had reflux quite bad when we were in the NICU and when we came home. Sleeping inclined was the only way we could get any rest.*
Monitoring		
Commercial device	*Safety.* (30 wk, current age 3 y) *Use a movement monitor.* (31 wk, current age 6 mo)	*We had a plate that monitored breathing and sounded an alarm as part of our baby monitor.* *Scared he will stop breathing as he had dsats and apneas in hospital.*
Visual monitoring	*Maintaining a good monitoring system.* (28 wk, 4 y 3 mo) *When he was initially discharged someone (myself or my husband) would stay up with him. To monitor him as he slept. Once we could not physically take being up that much anymore we purchased a monitor.* (31 wk, current age 1 y 7 mo)	*To make sure he wasnt having any difficulties in the night. In the NICU he had constant monitors & it was scary to bring him home knowing I was really his only monitor system.* *Looking back, mainly it was made out of fear. Fear that we would miss something while he slept.*
Infant-guided		
Sleep schedule	*Allowing her to dictate her sleep schedule and using a swaddle wrap to keep her contained.* (26 wk, current age 12 mo) *Making sure she actually sleeps through the night.* (30 wk, current age 1 y 10 mo)	*Her sleep in the NICU was constantly interrupted by alarms and lights and commotion, so it was difficult to establish a normal "schedule" for her. In the time since we've been home, we've allowed her to regulate her own sleeping patterns.* *She needs rest and recuperation to help her grow and stay healthy.*
Feeding schedule	*Once she regained birth weight we let her sleep up to 5 h at night for the first month and after that let her sleep until she was hungry again.* (35 wk, current age 2 mo)	*Initially she was very sleepy and not eating well.*

American[16,17,19] and American Indian infants,[13] this is one of the few studies to examine the decision-making process concerning sleep practices of mothers of preterm infants. The participants were recruited through social media postings of 2 organizations that provide services to parents of preterm infants. This approach resulted in a sample that represented all regions of the United States. The unintentional homogeneous demographics of the study participants reflect those of parents who use support groups for children with ongoing problems.[35] However, of interest, and also unanticipated, was that 64% of the mothers who responded had infants who were older than 12 months at the time of the survey, with the oldest child being 18 years of age. While it is not known why the participants had maintained a relationship with the organizations, the qualitative responses contained so much detail in responses of mothers with infants older than 1 year, there was no indication initially that the experiences that were being described were not recent. It is possible that mothers of infants who are beyond the period of risk for SIDS are more willing to report nonadherent sleep practices. This is supported in this study by the finding that nearly twice as many participants with infants older than 1 year reported co-sleeping, a practice that has been associated with infant death that was acknowledged by the mothers. Reasons for decisions had no differences between age groups; however, the report of worry, fear, and need to closely monitor the infant may reflect the psychological well-being associated with the experience of having a preterm infant in the NICU and continued connection with support groups.

Safe Sleep Practices

The adherence with SSR in this study was better than other studies that included preterm infants. Putting infants on their back to sleep consistently has the highest rate of adherence when compared with other SSR among studies. Dowling et al[26] reported 85% of preterm infants younger than 6 months slept on their back compared with 94.3% in this current study, while Damato et al[31] reported 80% of parents of preterm twins at 26 weeks put their infants on their back to sleep.

The low use of pacifiers at all times of sleep (22.9%) in the current study is consistent with other studies of preterm infants as having the lowest rate of compliance.[10,23,26,31] Interestingly, the use of pacifiers and breastfeeding were not identified as important decisions by any of the 98 mothers. This may be attributed to the universal recommendation for the provision of human milk and recommendation that pacifiers be avoided until breastfeeding is established.[3] Preterm infants have a longer time to establish full at breastfeeding,[36] and once it is established, mothers may be reluctant to start using pacifiers. In addition, the role of pacifiers to reduce the risk of SIDS is less clear than other recommendations.

The decision to continue the practice of inclining the mattress after hospital discharge for infants with a history of reflux is concerning and poses risk for compromise of the airway or suffocaiton.[3] Despite evidence that elevating the head of the crib and supine position have no effect on the frequency of reflux,[37] infants are routinely positioned with the crib at an incline as an intervention for reflux. Improved consistency and modeling of the SSR will increase the parents' continued practice after discharge.

Nonadherent Decisions to Reduce Risk for SIDS

The HBM guided this study by addressing the mothers' perceived vulnerability of their infant for SIDS. The model supports preventive health behaviors that are taken when people feel susceptible and are motivated to undertake a health behavior and action. The emotional and psychological stress of having a preterm infant in the NICU can lead to maternal feelings of anxiety and symptoms of posttraumatic stress disorder (PTSD).[38] Mothers' of preterm infants are found to have greater levels of anxiety and worry about their infant's health.[38,39] The impact of the stress experienced is heightened at 1 month postdelivery[38] and found to continue up to 2 to 3 years.[39] The effect of the long-term nature of PTSD is reflected in this study by the detailed descriptions of the anxiety participants felt in caring for their preterm infant at home, and the detail that was provided reflects the need for the mothers to have the opportunity to talk through their experiences.

Mothers expressed their ongoing concern that without close monitoring something would happen to their infant. Without confidence that the problems associated with apnea and bradycardia or other medical issues were resolved by discharge from the NICU, they needed to continue the monitoring that had been the safety net in the hospital. Consequently, the use of commercial infant monitors as a replacement for NICU monitors is not surprising. Preterm infants are on monitors in the NICU until just prior to their discharge and their removal can leave a parent feeling anxious in anticipation of taking their preterm infant home after hospitalization. Parents made decisions to change their own sleep practices in order to watch their infant while sleeping to take place of the monitors they became accustomed to in the NICU. Their need for sleep and need to monitor the infant during sleep influenced their decision to purchase commercially available devices in case something happened during sleep. However, the accuracy of commercial home monitors is not well studied and these monitors are not regulated by the US Food and Drug Administration.[40] In addition,

the 2016 AAP SSR advocates avoiding the use of cardiorespiratory monitors as a method of reducing SIDS.[8] A recent study found home pulse oximetry monitors to be inconsistent in their performance and had the potential to be dangerous rather than helpful.[40] Infant monitors are costly and although parents purchase and use the monitors for "'peace of mind," the lack of accuracy and regulation is concerning. An intentional step taken in hope of protecting the infant may indeed provide a false sense of security and actually increase risk.

Of most concern was the finding that 12% of the mothers in this study identified co-sleeping as the most important decision they made and were able to rationalize that closeness to the infant, and consequently the ability to closely monitor the infant's breathing, was more important than the acknowledged risk of suffocation. Although co-sleeping is frequently mentioned in both lay[36] and professional publications[3,12,20] as an approach to facilitating breastfeeding, it was not mentioned as a reason for that decision in this study. While in-bed and attached co-sleepers may be viewed as an acceptable compromise, they carry the risk of accidental suffocation if not used properly. There is a clear need to address this concern in teaching families.

Implications for Practice

The preterm population is growing: preterm births in the United States rose from 9.57% in 2014 to 9.85% in 2016.[26] Preterm infants are vulnerable and at a higher risk for SIDS, and these statistics highlight the ongoing need to improve our approach to the preparation of families to care for their preterm infant safely at home. Parents model care behaviors seen in the NICU,[25,32] so communicating effectively with parents during the hospitalization needs to include explanations for care interventions appropriate during hospitalization and again as the infant transitions to a back position to sleep and nears discharge. Safe sleep education is a standard part of discharge education for NICU nurses. The message on positioning infants on their back to sleep is being heard as evidenced by the consistent high compliance found in this study and others. That is not true for other SSR; however, including co-sleeping and pacifier use at the time of sleep may require a change in the approach to safe sleep education.

It is not clear if nurses tell parents that a preterm infant is at a greater risk for SIDS because of the infant's prematurity, but it should become part of the education. Education should include the rationale for each of the SSR, emphasize the unknown accuracy of home monitoring devices, provide advice on proper use of in-bed and attached co-sleepers to avoid risk of suffocation, and known increased risk of SIDS for preterm infants. The rationale for SSR may improve parents' understanding of how altering sleep practices can place their infant at greater risk. Discharge teaching should be tailored to individual family needs; asking parents what challenges they may have at home to adhering to the SSR as an initial step in addressing their concerns and helping them identify safe approaches. Parents need to be given the opportunity to share their feelings. As evidenced by the participants' comments in this study, the fears and anxiety that are associated with taking a preterm infant home are clearly remembered years later.

Implications for Research

While studies have examined sleep practices of mothers of term infants from minority populations, such as African American, it is essential that the present work be replicated to understand the factors behind the decision process for mothers of preterm infants who represent minority and disadvantaged

Summary of Recommendations for Practice and Research

What we know:	• Infant mortality is a national health concern, with 3600 infant sleep-related deaths reported annually. • Sleep practices change over time postdischarge for preterm infants. • Infant sleep practices reflect a lack of adherence to AAP SSR. • Decisions related to sleep practice can lead to unintentional risk for infants during sleep.
What needs to be studied:	• Additional studies to investigate decision making regarding infant sleep practices for preterm infants in diverse populations. • Future research to explore the impact of having a preterm infant in the NICU has on sleep practice at home over time. • Studies to evaluate education policies and practice for consistent use of safe sleep guidelines.
What can we do today that would guide caregivers in the practice setting considering use of this evidence for guiding practice:	• Nurses can model safe sleep practice prior discharge. • Consider including a rationale for each of the SSR and explanation of a preterm infant's greater risk for SIDS. • Assess for parent concerns for adherence to SSR at home. • Tailor safe sleep education to address barriers to safe sleep practice in the home.

socioeconomic populations. Parents reported perception of risk for their preterm infant is low, but their vigilance and need to keep them close to monitor them lead to nonadherence to SSR. Decisions made to monitor them unintentionally place the infant at higher risk. This phenomenon needs to be better understood to improve adherence to the SSR. Further research is needed to evaluate organizational education policies and consistent practice during hospitalization to improve adherence to SSR after discharge. Future research is needed to follow parents of preterm infants over a longer period of time to better understand the impact of emotional stress from the NICU experience has on adhering to SSR and determine reasons for use of support groups by mothers of preterm infants.

Limitations

Participants were recruited from an organization providing support to parents of preterm infants. Survey participants opinions may differ from those not part of an ongoing support group. The study sought to obtain a range of perspectives from diverse geographical locations through use of social media platform of 2 support organizations. While diverse in geographical region, the sample of participants was not representative of diversity in race, economic, or education status of mothers of preterm infants. The homogeneous demographics are a major limitation to the study; however, despite these limitations, this study is one of only a few in the literature to examine qualitatively the factors that influence the decisions concerning sleep practices made by mothers of preterm infants. Not knowing the actual time frame for sleep practices reported by mothers of infants older than 1 year is a limitation in this study. The survey questions for sleep practices need to be revised in future work.

CONCLUSION

Caring for a preterm infant can be challenging, and participants in this study expressed a heightened need to become the monitor to protect their infant once they are home following discharge from the NICU. Although well intended, there is potential that these parent decisions, intended for comfort and safety, indeed place infants at a greater risk for SIDS. The participation in the study by mothers with children well over 1 year of age reflects the impressionable and long-lasting memory of the experience of having an infant in the NICU. The detailed recall of the time after coming home from the NICU was unexpected, given the current age of the child.

Sleep-related deaths for infants younger than 1 year, especially for the most vulnerable preterm infant, are a major health concern. Barriers need to be addressed prior to discharge to tailor education based on the home sleep environment to increase the mothers' knowledge on the importance of adherence to AAP SSR and the increased risk of SIDS for preterm infants. Providing education on the recommendations may not be enough, and nurses need to include the rationale behind each SSR and implement strategies to assess the parents' barriers or anxiousness to tailor education to optimize adherence to the SSR.

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