Understanding the Barriers and Facilitators to Safe Infant Sleep for Mothers of Preterm Infants

Sunah S. Hwang, MD MPH PhD1, Margaret G. Parker, MD, MPH2,3, Bryanne N. Colvin, MD4, Emma S. Forbes, BA3, Kyria Brown, BA5, Eve R. Colson, MD, MHPE4
1Section of Neonatology, Department of Pediatrics, University of Colorado School of Medicine
2Department of Pediatrics, Boston Medical Center, Boston University School of Medicine
3Slone Epidemiology Center, Boston University School of Medicine
4Department of Pediatrics, Washington University School of Medicine
5Graduate School of Social Work, Colorado School of Public Health

Abstract

Objective: To identify barriers and facilitators to adherence to safe sleep practices (SSP) among mothers of preterm infants using qualitative methodology.

Design: We conducted 23 in-depth interviews in English or Spanish with mothers of preterm infants who were recently discharged from 4 hospitals, utilizing a grounded-theory approach and framework of the Theory of Planned Behavior (attitudes, perceived control, social norms).

Results: For attitudes, mothers’ fear about their infants’ vulnerable preterm state related to suffocation, apnea of prematurity, and reflux influenced infant sleep practices. For social norms, education received in the NICU and advice from other healthcare providers, family, friends, and media impacted their choices. For perceived control, mothers adapted infant sleep practices to meet their own needs and address the perceived safety and comfort of infants.

Conclusion: Factors identified that influence maternal decision-making about infant sleep practices can inform interventions to address sudden unexpected infant death reduction in preterm infants.

Keywords
SUID; SIDS; Prematurity; NICU
Introduction

Of the nearly 4,000,000 infants born in the US each year, approximately 10% are born preterm, defined as having a gestational age less than 37 weeks. Preterm infants are 2 to 3 times more likely to suffer sudden unexpected infant death (SUID), defined as “the death of an infant less than 1 year of age that occurs suddenly and unexpectedly, and whose cause is not immediately obvious prior to an investigation”. Nearly 3,700 infants die from SUID in the U.S. each year, making it the leading cause of post-neonatal mortality, with little improvement in rates in nearly two decades. During the first year of life, one of the most effective and modifiable parental behaviors to reduce the risk for SUID is adhering to safe infant sleep practices. The American Academy of Pediatrics (AAP) recommends that all infants under 1 year of age room share but not bed share with their caregiver and be positioned supine to sleep in a safe sleep environment, which consists of a separate sleep area that is flat, without blankets or other loose items. Despite these recommendations, parental adherence to these guidelines remains variable. Moreover, some studies have demonstrated lower adherence to supine sleep positioning among mothers of preterm infants compared to mothers of term infants.

While factors that impact maternal decision-making related to infant sleep practices for term infants are well documented in the literature, data are lacking for the preterm population despite their higher risk for SUID. Given the prolonged hospitalization of preterm infants in the neonatal intensive care unit (NICU), there is potentially a greater opportunity to engage caregivers about safe infant sleep practices. To develop effective interventions to meet the unique needs of the preterm population, a greater understanding of factors that impact maternal decision making about safe sleep practices is needed. Thus, the objective of this study was to determine perceived barriers and facilitators of adherence to AAP recommended safe sleep practices and other factors that may impact decision-making regarding sleep practices among mothers of preterm infants.

Methods

Design

We conducted a qualitative study through in-depth interviews of mothers of preterm infants, using the theory of planned behavior (TPB) as a framework. Developed by Icek Ajzen in the 1980’s, the TPB states that an individual’s intention to perform a certain behavior is determined by the attitude toward the behavior (the degree to which a person has a favorable or unfavorable opinion of the behavior), the subjective norm of that person (the likelihood that influential people surrounding an individual approve or disapprove of the behavior), and the perceived behavioral control (an individual’s confidence in his or her ability to carry out the behavior). This framework has been previously used by investigators to study maternal decision-making about infant care practices.

Purposeful Sampling Strategy

We sought to obtain a diverse range of perspectives and therefore recruited mothers of preterm infants from four hospitals with level 3 and 4 NICUs in three U.S. states. We
recruited mothers from Boston Medical Center in Boston, MA, where approximately 50% of patients identify as non-Hispanic Black and 25% as Hispanic, from Saint Louis Children’s Hospital in St. Louis, MO, where approximately 30% identify as non-Hispanic Black and 3% as Hispanic, and from two hospitals in Aurora, CO. At the Children’s Hospital Colorado, approximately 5–10% of patients identify as non-Hispanic Black and 30% identify as Hispanic, and at University of Colorado Hospital, less than 5% identify as non-Hispanic Black and approximately 40% identify as Hispanic. Regarding unit-level safe sleep practices and policies, the Boston unit participates in the Massachusetts Hospitals Safe Infant Sleep Quality Improvement Collaborative which is focused on integrating safe sleep practices weeks to months prior to NICU discharge if the infant is medically-eligible. For the unit in St. Louis, infants are considered “safe sleep ready” when they are in a crib, not requiring high flow nasal cannula, and ≥ 32 weeks gestation. They are then placed on their backs with unsafe objects removed from the crib. For the Colorado NICUs, infants are considered eligible for safe infant sleep practices when they are feeding orally 50% of their enteral feeds and on low flow nasal cannula. For all units, parents receive education related to safe infant sleep prior to hospital discharge.

We recruited mothers by phone or in-person of any age who spoke English or Spanish, gave birth to their infants < 37 weeks’ gestation, and had infants hospitalized in the NICU for at least 7 days. Consent was obtained at the time of initial contact and interviews were conducted at a later time when the infants had been home from the hospital for 2–6 months in order to gain perspectives of mothers that experienced prolonged mother-infant separation during the infant hospitalization and transitioned from hospital to home. We conducted 23 one-on-one interviews by phone and via videoconference from January to June 2019. To reduce the possibility of bias across interviewers, all interviewers (M.P., E.F., C.P., I.H., K.B.) were trained to conduct in-depth interviews by one experienced qualitative researcher (E.C.) with the interview guide developed and agreed upon by all interviewers. For Spanish-speaking mothers, interviews were conducted by two native Spanish-speaking interviewers (C.P., I.H.) who also translated these Spanish transcripts into English. Mothers received a $40 gift card incentive for participation. The Institutional Review Boards of all institutions approved the study.

Data Collection

We constructed an interview guide with probe questions focused on the TPB domains of attitudes, perceived control and social norms related to infant sleep practices with the goal of identifying facilitators and barriers to following safe sleep recommendations. Questions were asked in an open-ended format. After analyzing transcripts and discussing results through investigator triangulation, we revised the question guide and added probe questions as new ideas were discovered. The in-depth semi-structured interviews were conducted in English or Spanish by one of 5 trained team members. Interviews lasted 30 to 60 minutes and were audiotaped and transcribed verbatim. Interviews in Spanish were additionally translated into English. Basic demographic and health data were abstracted from the medical record for the purposes of describing the study population.
Data analysis

We utilized a systematic, iterative process of data collection and analysis, consistent with a Grounded Theory approach informed by the TPB framework. Each transcript was reviewed by investigators (M.P, S.H., E.F, E.C. and B.C.), with expertise in neonatology, general pediatrics, qualitative analysis, social work, and infant sleep practices. To maximize trustworthiness of the analysis, each transcript was independently reviewed by three members of the group to identify tentative codes. The group met at regular intervals to review and revise the coding structure before independently coding the transcripts and meeting again to assure uniform coding of each transcript. Any disagreements were resolved through group discussion. An iterative approach to data analysis allowed the team to continuously refine interview questions, develop themes, and monitor for thematic saturation. Data collection ended when thematic saturation was reached (no new themes identified.)

Results

Participant characteristics

Participant characteristics can be found in Table 1. The average gestational age of infants at time of delivery was 33 weeks, ranging between 25 and 36 weeks’ gestation. Two infants were less than 29 weeks in gestation, 11 infants were 29–33 weeks gestation, and 10 infants were 34–36 weeks in gestation. In general, mothers of infants who were younger in gestation expressed greater concerns about respiratory and feeding issues which impacted their decision-making about infant sleep practices. 35% of mothers were non-Hispanic Black, 30% were non-Hispanic white, and 30% were Spanish-speaking. Three (13%) of the participants were mothers of multiples.

Attitudes

Maternal attitudes about their preterm infants’ safety as well as overall comfort influenced their infant sleep practices. Regarding safety, mothers had very different views of which sleep practices were safe for a small and/or vulnerable preterm infant, specifically due to concern about suffocation, apnea of prematurity, and reflux. While some views of optimal safe sleep practices were consistent with AAP recommendations, others were in direct contrast.

Regarding the fear of suffocation, some mothers reported avoiding sharing the same sleep surface with their infants at all costs due to concerns of suffocation. One mother expressed the fear of sharing a sleep surface with her infant, but also maintained vigilance by having the infant in close proximity to her. She stated, “…she’s too small…because when we are sleeping you don’t really know what’s happening. So, it’s better if she’s on her bed instead of ours…And when she’s close to me she can cry. . . But we don’t put her in our bed when we’re sleeping because something can happen you know.” In contrast, for other mothers, bed sharing was perceived as the best practice to most effectively watch their infants who they felt to be vulnerable. One mother whose infant was discharged home from the NICU on oxygen said, “She spent a month with oxygen so I had to keep very close watch of her...
because she was on oxygen day and night, so at first I slept with her...she slept with me on the bed…”

In addition to fear of suffocation, fear of apnea/bradycardia events (i.e., “spells”) that mothers witnessed in the NICU influenced their infant sleep practices. Despite maternal knowledge that home monitors do not “pick up” spells that may lead to respiratory complications and possibly SUID, some mothers reported purchasing home monitors anyway. One mother stated, “[prematurity and spells] went into my decision to get monitors for them at home even though I know there’s not evidence necessarily that those prevent SIDS. It’s something else that I feel like gives me some peace of mind.” For several mothers, the unpredictability of infant “spells” that they experienced in the NICU magnified their desire to maximize vigilance and visual and electronic monitoring at home.

Mothers were also fearful of breathing difficulties due to reflux and vomiting, and selected certain infant sleep locations and positions to minimize this perceived risk. Several mothers perceived that having their infant in an inclined position reduced the risk for choking due to reflux. Again, while this practice is in contrast to AAP recommendations for a completely flat sleep position, several mothers chose the inclined position. One mother shared that “when [the baby] first got home, she pretty much had to sleep upright…I would have her sitting up in her bouncer, propped up in an upright position so if she was to reflux, because she has that really bad…her milk sticks in the middle of her throat and she’s started coughing and choking before on her back, so that’s what prompted me to sit her upright, so if she was to reflux it would just flow out the side of her mouth instead of her choking on it coming back down.”

In addition to the fear rooted in their infants’ vulnerability as preterm infants, maternal attitudes toward their infants’ comfort also influenced infant sleep practices. In general, mothers perceived their infants as uncomfortable if crying and having greater comfort when they slept for longer periods of time. To enhance this perceived infant comfort, mothers reported using devices that had constant movement, placing infants to sleep on their chest, and/or placing their infants in a side or stomach position. One mother shared that she chose to use moving devices for infant sleep because they allowed for longer sleep duration, stating that her baby “likes the feeling of being moved. The swing is really good for that… the rock ‘n play vibrates; it just gives him a little bit of soothing movement to keep him asleep for longer.” Along with movement, several mothers felt that certain sleep positions were not tolerated by their infants. Again, despite AAP recommendations, the perceived comfort of their infants often had greater influence over their decision making about sleep position. For instance, one mother shared, “…it was just every time we’d put him on his back, he’d either instantly wake up screaming or he would roll on his own to his side or his stomach and we learned just if we automatically put him on his side or his stomach, he never would wake up, he would just continue his nap.”

Social norms

For mothers of preterm infants, social norms related to infant sleep practices were established across the perinatal time period. Mothers reported having trust in various sources
of advice about safe infant sleep, including health care providers in the NICU and outpatient settings, family members, friends, and other information sources.

Regarding education in the NICU, mothers shared how the sleep practices they adopted at home were influenced by what they heard, read, and observed in the NICU. While most mothers reported receiving education and observing sleep practices that were concordant with AAP recommendations, others mentioned seeing sleep practices that were in contrast to AAP recommendations. For instance, one mother shared that “when [the baby] was in the NICU, he mostly was on his side. So, he kind of liked the side better than he did the back.” Notably, this mother highlights that her infant appeared to have become accustomed to and hence more comfortable with the side position because this was how he was usually placed in the NICU. However, another mother reported noticing supine positioning modeled in the NICU and as well as being recommended by NICU providers. She stated that her infant was positioned on his back “because it’s the safest way for a baby to sleep and I don’t want him to like roll on his face or stuff like that … that’s how he used to sleep when he was in the NICU, too. They would always say that that’s the safest way he would sleep so I just don’t want no mistakes so that’s what I’d do.” Several mothers of preterm infants perceived that the sleep practices they observed during NICU hospitalization were safest, demonstrating the impact of modeling on maternal decision making.

In addition to verbal education and modeling in the NICU, maternal social norms related to infant sleep were shaped and reinforced through other forms of education and sleep-related items which were used in the NICU or given to families at discharge. Several mothers reported watching safe sleep educational videos and also receiving sleep-related items such as swaddle blankets or sleep sacks. One mother shared how she had changed her infant’s sleep environment after watching an infant sleep video during NICU hospitalization. She shared, “When we were at [the hospital] they had all these videos that we had to watch. Because I remember like on my registry I did order the baby bumpers because…it was part of the set and it was super cute. And then you watch these videos about bumpers and you’re like, oh, we’re not going to have it. We immediately took the bumpers down.” The provision of sleep related supplies by the NICU also influenced maternal sleep practices at home. Several mothers noted that their infants were placed to sleep in sleep sacks and were also given a sleep sack at the time of discharge for use at home. One mother shared how even after hospital discharge, she continued to purchase the sleep sacks that were like the ones she had received from the hospital.

After discharge from the NICU, mothers reported receiving advice about infant sleep practices from their pediatricians. In general, mothers reported receiving advice that was in line with AAP recommendations. These mothers seemed to trust the infant sleep advice of their pediatricians and followed their recommendations. For instance, one mother initially had her infant sleep in a separate room from where she slept, but after seeing the pediatrician, she reported, “A few days later I came to see the pediatrician and I told him that he was sleeping alone in his bedroom, with his brother, and he said that at least for the first year, or the first six months, it was good for him to sleep with me in my bedroom. So, that’s also why I decided to move him, because he said that. I decided to move his cradle to my bedroom.”
Besides health care providers, mothers mentioned the impact of their partners, other children, parents, grandparents, and friends on their infant sleep practices. Some mothers reported that advice from friends or family was not concordant with recommendations from health care providers and thus decision making about infant sleep was more complicated. For instance, one mother stated, “I like to go to my parents for some things, but because they’re like old-school and they do everything by the old-school book that’s not written anywhere, it’s hard to go by their advice on things. And my mom’s like, “Oh, your sister used to spit up a lot. Put [the baby] in the car seat…I used to put your sister in the car seat. Put him in the car seat, have him sit up.” And I’m like, like I asked the doctor…his doctor or nurse doesn’t say that that’s okay…I just wouldn’t trust [my mom’s] information.” Some mothers of preterm infants interviewed in our study trusted the advice from medical providers over family or friends, recognizing that their preterm infants were not like the healthy full-term infants their family and friends may be more familiar with.

Mothers also reported researching information about infant sleep practices on the Internet and social media, and some recognized that the information they procured online was not in agreement with practices recommended by health care providers. Again, most mothers of preterm infants we interviewed trusted the medical providers, particularly, those in the NICU, about infant sleep advice over what they read from other sources. However, during interviews with some other mothers, it was not entirely clear if they followed the advice from non-medical sources that differed from AAP recommendations. For example, one mother spoke about a Facebook group for mothers of twins and stated, “…I do see people, you know, like posting stuff that they do for their twins that, you know, like I know is not recommended, you know, but the person that doesn’t have a job in the medical field or in like a NICU setting might not know that and you’re just going along with what, you know, what’s working for them.”

Perceived control

Mothers of preterm infants shared how their sense of control over their infants’, as well as their own, health and wellbeing informed their approach to infant sleep. Mothers stated several reasons for adopting sleep practices that they knew were considered unsafe, including the perception that co-sleeping allowed for greater ease of breastfeeding, their own fatigue, and their perception of the infants’ comfort. For instance, one mother expressed understanding of the dangers of co-sleeping but felt that the advantages of co-sleeping to foster breastfeeding outweighed the risk. She stated, “I appreciate that [it is] not an AAP recommendation to co-sleep with your baby, but I feel like I try and weigh all of this and make sure that I can continue breastfeeding that’s as safe as possible for my babies.”

This approach of weighing risks versus benefits of co-sleeping and of risk mitigation was mentioned by several mothers in our study. While they recognized that some of the infant sleep practices they adopted were not recommended by the AAP, particularly co-bedding, mothers sought to reduce the risk for potential suffocation by making adjustments which they perceived to offer some safety. One mother who was struggling with lack of sleep discussed how other groups aided her risk mitigation approach and allowed her to have more control over the situation. She stated, “…the Leche League and the nurse family partners
coached me on [co-sleeping] and how to make it safe. So I felt confident in doing it and that was really the game changer because I wasn’t sleeping. So once we found a way to [safely co-sleep], that’s what made a huge difference for us was the co-sleeping.” Another mother provided more specific details on her many strategies to reduce the risk of suffocation incurred from co-sleeping. She shared, “So, typically I’m on my side and [the baby] is right next to me and I form a C around him to make sure that he’s protected. My husband’s a little bit of a crazy sleeper, but I – I’m all around him, so that way if my husband starts rolling over towards me, I feel him and I can push him away. So, that’s what we do. Typically, he’s on his back when I lay him down, and then – but he usually rolls over to his side and cuddles me. But in general, that’s how we sleep, he’s just right next to me. He’s usually in the middle of the bed, so that way we don’t have the risk of him falling off the bed.”

Mothers’ perceived control over their infants’ sleep positioning and environment was also influenced by family members and friends. The mothers we interviewed with caregivers that adhered to the same sleep practices felt more control, whereas mothers with caregivers that did not adhere to their preferred sleep practices felt less control. One mother who returned to work stated, “When I’m at work, my husband is either with my daughter or my cousin watches her or my mom. They follow the same sleep guidelines I do.” However, other mothers noted that when infants were cared for by other family members, they lacked control over how their infants slept as the sleep practices varied from what was typically done by the mother. For instance, another mother shared, “when [the baby] is at his grandparents’ house, they have a little makeshift bed set up for him on the couch where they’ve got stuff to block it so he can’t roll off the couch. He’s usually on a softer blanket on the couch cushion and he’s usually covered up when he sleeps…If he [falls] asleep on the floor doing tummy time…, grandma just throws a blanket over his legs so he doesn’t get cold and lets him sleep till he decides to wake up…or he falls asleep in a swing and usually, he has a blanket when he’s in the swing.” In general, in instances where other caregivers did not follow the same sleep practices as the mother, the sleep positioning and environment were not in-line with AAP recommendations.

Additional factors such as maternal employment status, the presence of other children in the home, and the physical space in the home impacted maternal decision-making by facilitating or hindering adherence to AAP recommendations. For instance, one mother who worked outside of the home and needed more sleep had to alter her infant sleep practices to meet her needs. She shared, “I bought a firm mattress that’s separate from the mattress in my room and … put one tight fitting sheet on it and I put it on the floor so that I can try and make [co-sleeping] as safe as possible to do so and it’s something that I’ve done usually when I go back to work with my kids … to get more sleep and also continue breastfeeding. Because there are times when I take 30, 40-hour shifts and I come home and I do need to sleep, so I’ll have them on their backs, but next to me only, no pets, no other kids, no one else, and then with the pulse oximeter monitor on them.” Interestingly, in other situations, mothers were perhaps unintentionally compliant with AAP recommendations due to convenience and need. One mother with two other children and a limited number of bedrooms stated, “Because I got my mobile house… and I have a 9-year-old boy and my daughter is 7 … each one has their own room and so [the baby] sleeps in my room.” It appears that this
mother adopted the recommendation of room sharing because there was no other room for the baby to sleep once the bedrooms were occupied by other children.

Discussion

Utilizing the theory of planned behavior, we identified factors that facilitated as well as hindered adherence to AAP safe infant sleep recommendations and other factors that influenced decision-making regarding safe sleep practices. For attitudes, mothers’ fear about their infants’ vulnerable preterm state, especially related to suffocation, breathing difficulties related to apnea of prematurity, and reflux, all influenced mothers’ infant sleep practices. In addition, maternal perception of their infants’ comfort impacted their decision making. For social norms, the education mothers received in the NICU as well as advice received from other health care providers, family, friends, and the media impacted their choices. Finally, for perceived control, mothers adapted infant sleep practices to meet their own needs as well as the perceived safety and comfort of their infants. We found that the presence of other caregivers and their infant sleep practices were in accordance with or in direct contrast to the mothers’ infant sleep choices.

While some of our findings are similar to what has been demonstrated for mothers of term infants, several are unique to the preterm population. In terms of similarities, concerns of airway obstruction due to reflux and vomiting were attitudes among mothers of term infants in prior qualitative studies. A desire to optimize infant comfort by minimizing crying and promote longer infant sleep has also been described in term infants. Previous studies of term infants also describe adoption of risk mitigation strategies by mothers who weighed the risks versus benefits of certain infant sleep practices. Several mothers in our study recognized the potential dangers of co-sleeping, but still felt that this sleeping arrangement allowed for easier breastfeeding, longer sleep duration, and closer monitoring of their infants.

Among mothers of preterm infants, social norms related to infant sleep practices were shaped by health care providers within the NICU as well as in the outpatient setting. In addition, family, friends and media sources influenced maternal decision making. While similar findings have been demonstrated among mothers of term infants, a notable difference among mothers of preterm infants was the tremendous impact that hospital-based education and infant sleep modeling had on maternal choice for certain infant sleep practices. In contrast to the weeks and months of many preterm infant hospitalizations, the duration of birth hospitalization of healthy term infants typically lasts only 1–4 days, with the infant remaining in the postpartum room with mothers. A recent cluster randomized clinical trial of mothers of healthy term infants assessed the effectiveness of two safe sleep education interventions—one delivered by nurses during the brief, birth hospitalization and one that occurred through text and email videos after discharge for several weeks. The brief hospital intervention had minimal effect compared to the post-discharge intervention. The lack of impact of the hospital-based intervention may have been due to the short duration of hospital education for healthy term infants.
In contrast, the prolonged NICU hospitalization may provide great opportunity for education about and exposure to modeling of recommended safe sleep practices. Recent single and multi-NICU site studies have demonstrated that integration of standardized approaches to safe sleep practices during NICU hospitalization among medically stable preterm infants leads to high compliance with AAP recommended safe sleep practices.22–24

One of the most frequent concerns that mothers of preterm infants expressed was the vulnerability and “smallness” of their infants. When infants were finally discharged home, mothers felt hyper-vigilant about the safety of their infants, prompting them to adopt infant sleep practices that they perceived to be the safest for their vulnerable infants. Some of these practices, such as supine positioning and room sharing but not bed sharing, were concordant with AAP recommendation, while other practices such as bedsharing, side or prone positioning, and inclined positioning were in direct contrast to recommended practice. Prior studies have focused on parental perceptions of vulnerability of formerly preterm infants and the impact on infant development and health care utilization.25–27 Our study is one of the first, to our knowledge, that investigates how maternal perception of vulnerability in their preterm infants influences their decision making related to sleep practices.

There are several implications from this study. First, some factors that impact decision making related to infant sleep practices for mothers of preterm infants may be similar to those for mothers of term infants, but there are several that do vary. The unique experience of mothers of preterm infants with prolonged mother-infant separation during the NICU hospitalization and the ways in which these experiences influence maternal sleep practices requires additional study. It is likely that the interventions that have demonstrated effectiveness in improving safe infant sleep practices in the healthy term population may not resonate with mothers of preterm infants who have had starkly different prenatal, birth, and postnatal experiences. Thus, population-based studies of factors that impact decision-making about infant sleep practices for families of preterm infants are needed in order to inform the development of intervention trials specifically targeted to the preterm population.

Second, our interviews with mothers of preterm infants demonstrate that other caregivers beyond mothers and fathers should be included in hospital- and community-based infant sleep interventions. In several instances, mothers reported that while they adopted AAP recommended safe sleep practices, when their infants were being cared for by other family members or friends, the same practices were not always adopted. This finding is certainly not unique to the preterm population as prior studies of the general population of infants have shown that nonparent caregivers including grandmothers and childcare centers have suboptimal compliance with AAP recommendations.28,29 Moreover, an analysis of sleep-related infant deaths from 2004 to 2014 in the National Center for Fatality Review and Prevention Child Death Review Case Reporting System found that infants who died under nonparental supervision had higher adjusted odds of being found in the prone position and among infants who died, those cared for by relatives or friends were more likely to be placed on an adult bed or couch for sleep and bed sharing, and to have objects in the sleep environment.30
There are several limitations to this study. While we did recruit mothers from 4 different NICUs in three U.S. cities, our sample may not be representative of the general population of mothers of preterm infants. In addition, we included only mothers who spoke English or Spanish and thus were not able to capture the experiences of mothers who spoke other languages.

Despite these limitations, our study is one of the first to present the qualitative experience of mothers of preterm infants related to safe infant sleep practices. Over one-third of our cohort was comprised of non-Hispanic Black mothers, allowing us to ensure that the experiences of Black mothers of preterm infants were represented, a critical element since Black and preterm infants bear a greater risk for SUID.

**Conclusion**

In conclusion, in this qualitative study of mothers of preterm infants from 4 NICUs in 3 U.S. states, we demonstrate that various factors which shape maternal attitudes, social norms, and perceived control related to infant sleep practices are both barriers and facilitators to maternal adherence to AAP recommendations. Mothers of preterm infants are unique in their experiences, and therefore need tailored interventions, which are informed by these experiences, to effectively improve safe infant sleep practices after NICU discharge.

**Acknowledgments**

**Funding:** National Institute of Child Health and Human Development (1R01HD095060-01; to M.P. and S.H.)

**References**

1. Martin JA, Hamilton BE, Osterman MJK, Driscoll AK. Births: Final Data for 2018. Natl Vital Stat Rep. 2019;68(13):1–47.
2. Malloy MH. Prematurity and sudden infant death syndrome: United States 2005–2007. J Perinatol. 2013;33(6):470–475. [PubMed: 23288251]
3. Prevention CfDCa. Sudden Unexpected Infant Death and Sudden Infant Death Syndrome. https://www.cdc.gov/sids/about/index.htm. Accessed June 1, 2020.
4. Kochanek KD, Murphy SL, Xu J, Tejada-Vera B. Deaths: Final Data for 2014. Natl Vital Stat Rep. 2016;65(4):1–122.
5. Moon RY, Task Force On Sudden Infant Death S. SIDS and Other Sleep-Related Infant Deaths: Evidence Base for 2016 Updated Recommendations for a Safe Infant Sleeping Environment. Pediatrics. 2016;138(5).
6. Colson ER, Rybin D, Smith LA, Colton T, Lister G, Corwin MJ. Trends and factors associated with infant sleeping position: the national infant sleep position study, 1993–2007. Arch Pediatr Adolesc Med. 2009;163(12):1122–1128. [PubMed: 19996049]
7. Colson ER, Willinger M, Rybin D, Heeren T, Smith LA, Lister G, et al. Trends and factors associated with infant bed sharing, 1993–2010: the National Infant Sleep Position Study. JAMA Pediatr. 2013;167(11):1032–1037. [PubMed: 24080961]
8. Hirai AH, Kortsmit K, Kaplan L, Reiney E, Warner L, Parks SE, et al. Prevalence and Factors Associated With Safe Infant Sleep Practices. Pediatrics. 2019;144(5).
9. Hwang SS, Lu E, Cui X, Diop H, Barfield WD, Manning SE. Home care practices for preterm and term infants after hospital discharge in Massachusetts, 2007 to 2010. J Perinatol. 2015;35(10):880–884. [PubMed: 26248131]
10. Hwang SS, Smith RA, Barfield WD, Smith VC, McCormick MC, Williams MA. Supine sleep positioning in preterm and term infants after hospital discharge from 2000 to 2011. J Perinatol. 2016;36(9):787–793. [PubMed: 27171759]

11. Ajzen I. The Theory of Planned Behavior. In: Organizational Behavior and Human Decision Processes. Vol 50.1991:179–211.

12. Smith LA, Geller NL, Kellams AL, Colson ER, Rybin DV, Heeren T, et al. Infant Sleep Location and Breastfeeding Practices in the United States, 2011–2014. Acad Pediatr. 2016;16(6):540–549. [PubMed: 26851615]

13. Colson ER, Geller NL, Heeren T, Corwin MJ. Factors Associated With Choice of Infant Sleep Position. Pediatrics. 2017;140(3).

14. HR B. Research Methods in Anthropology: Qualitative and Quantitative Approaches. 3rd Edition ed. Walnut Creek, CA: Altamira; 2002.

15. Denzin NKal YS. The Sage Handbook of Qualitative Research. 3rd Edition ed. Sage Publications; 2006.

16. Colson ER, Levenson S, Rybin D, Calianos C, Margolis A, Colton T, et al. Barriers to following the supine sleep recommendation among mothers at four centers for the Women, Infants, and Children Program. Pediatrics. 2006;118(2):e243–250.

17. Oden RP, Joyner BL, Ajao TI, Moon RY. Factors influencing African American mothers’ decisions about sleep position: a qualitative study. J Natl Med Assoc. 2010;102(10):870–872, 875–880. [PubMed: 21053701]

18. Pease A, Ingram J, Blair PS, Fleming PJ. Factors influencing maternal decision-making for the infant sleep environment in families at higher risk of SIDS: a qualitative study. BMJ Paediatr Open. 2017;1(1):e000133.

19. Ajao TI, Oden RP, Joyner BL, Moon RY. Decisions of black parents about infant bedding and sleep surfaces: a qualitative study. Pediatrics. 2011;128(3):494–502. [PubMed: 21859921]

20. Hwang SS, Rybin DV, Heeren TC, Colson ER, Corwin MJ. Trust in Sources of Advice about Infant Care Practices: The SAFE Study. Matern Child Health J. 2016;20(9):1956–1964. [PubMed: 27129949]

21. Moon RY, Hauck FR, Colson ER, Kellams AL, Geller NL, Heeren T, et al. The Effect of Nursing Quality Improvement and Mobile Health Interventions on Infant Sleep Practices: A Randomized Clinical Trial. JAMA. 2017;318(4):351–359. [PubMed: 28742913]

22. Gelfer P, Cameron R, Masters K, Kennedy KA. Integrating “Back to Sleep” recommendations into neonatal ICU practice. Pediatrics. 2013;131(4):e1264–1270.

23. Hwang SS, O’Sullivan A, Fitzgerald E, Melvin P, Gorman T, Fiascone JM. Implementation of safe sleep practices in the neonatal intensive care unit. J Perinatol. 2015;35(10):862–866. [PubMed: 26156063]

24. Hwang SS, Melvin P, Diop H, Settle M, Mourad J, Gupta M. Implementation of safe sleep practices in Massachusetts NICUs: a state-wide QI collaborative. J Perinatol. 2018;38(5):593–599. [PubMed: 29410541]

25. Allen EC, Manuel JC, Legault C, Naughton MJ, Pivor C, O’Shea TM. Perception of child vulnerability among mothers of former premature infants. Pediatrics. 2004;113(2):267–273. [PubMed: 14754937]

26. Culley BS, Perrin EC, Chaberski MJ. Parental perceptions of vulnerability of formerly premature infants. J Pediatri Health Care. 1989;3(5):237–245. [PubMed: 2778593]

27. McCormick MC, Shapiro S, Starfield B. Factors associated with maternal opinion of infant development--clues to the vulnerable child? Pediatrics. 1982;69(5):537–543. [PubMed: 7079008]

28. Aitken ME, Rose A, Mullins SH, Miller BK, Nick T, Rettiganti M, et al. Grandmothers’ Beliefs and Practices in Infant Safe Sleep. Matern Child Health J. 2016;20(7):1464–1471. [PubMed: 26987862]

29. Gershon NB, Moon RY. Infant sleep position in licensed child care centers. Pediatrics. 1997;100(1):75–78. [PubMed: 9200363]

30. Lagon E, Moon RY, Colvin JD. Characteristics of Infant Deaths during Sleep While Under Nonparental Supervision. J Pediatriatr. 2018;197:57–62 e36. [PubMed: 29622341]
Table 1.

Participant Characteristics

|                                      |         |
|--------------------------------------|---------|
| Number of individual interviews      | 23      |
| Maternal age (years)                 | 34 (21–38) |
| Infant gestational age at birth (weeks) | 33 (25–36) |
| Infant birth weight (grams)          | 1770 (790–2980) |
| N (%)                                |         |
| Non-Hispanic Black, English-speaking | 8 (34.8%) |
| Hispanic (any race), English-speaking | 1 (4.3%)  |
| Hispanic (any race), Spanish-speaking | 7 (30.4%) |
| Multiples                            | 3 (13%) |
| Mothers who smoked in the 6 months before or during their pregnancy | 4 (17.4%) |