DOI: 10.1097/JPN.0000000000000345

J Perinat Neonat Nurs • Volume 32 Number 4, 366–372 •

Caring about Preemies' Safe Sleep (CaPSS)

An Educational Program to Improve Adherence to Safe Sleep Recommendations by Mothers of Preterm Infants

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ABSTRACT

Preterm infants born before 37 weeks' gestation die of sudden infant death syndrome (SIDS) at a rate more than double that of term infants. There is a need for SIDS prevention programs tailored to the specific needs of parents of high-risk infants. The purpose of this study was to pilot test an online educational module addressing SIDS risk-reduction recommendations (RRRs) for parents of preterm infants. This study was conducted in a 44-bed transitional care unit at a level IV NICU in the Midwest. A repeated-measures design was used. Two weeks before discharge, mothers completed a survey, addressing knowledge and plans for caring for their baby at home. Mothers then viewed the 5-section Caring about Preemies' Safe Sleep (CaPSS) education module and completed the postmodule evaluation. A discharge survey was completed 4 weeks postdischarge. Fifteen mothers, mean age 26.4 years, participated; 8 (53%) returned the postdischarge survey. Module evaluation rated clarity and completeness of information high. Mothers' ratings of SIDS knowledge were significantly higher after viewing the module ($P = .000$) and 4 weeks after discharge home ($P = .012$). Mothers found the use of a pacifier at sleep times to be new information and changed their plans for caring for their infant, with 28.6% of mothers always offering a pacifier before sleep after discharge compared with the 6.7% who had planned to do this before discharge. However, only 71% of infants slept in parents' room after discharge and only 41% were receiving at least some breast milk, which are not consistent with SIDS RRRs.

Key Words: education, preterm infant, sudden infant death syndrome

Despite the remarkable decrease in the rate of sudden infant death syndrome (SIDS) after the "Back to Sleep" campaign began in 1992, SIDS remains the fourth leading cause of infant death in the United States and the second leading cause of death beyond 1 month of age, a death rate that has not changed since 2001.[1] In 2011,[2] and again in 2016,[3] the American Academy of Pediatrics (AAP) released new recommendations for safe sleep, which are categorized as A, B, or C recommendations based on the strength of research evidence. In 2011, the risk-reduction recommendations (RRRs) included for the first time the importance of breastfeeding (level A). Unchanged level A recommendations included use of a firm sleep surface; absence of soft objects and loose bedding in the crib; room sharing without bed sharing; and offering a pacifier at sleep times. In addition, these recommendations included, for the first time, the larger category of sudden unexpected infant deaths (SUIDs) that occur during sleep and collectively aim to "reduce the risk of all sleep-related infant deaths," including deaths attributed to strangulation

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This work was supported by a Research Initiative Grant from Frances Payne Bolton School of Nursing, Case Western Reserve University.

Disclosure: The authors have disclosed that they have no significant relationships with, or financial interest in, any commercial companies pertaining to this article.

Each author has indicated that he or she has met the journal's requirements for Authorship.

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Submitted for publication: January 4, 2018; accepted for publication: April 14, 2018.

and suffocation.[4] Healthy People 2020 has targeted both SIDS and SUID mortality rates, aiming at a 10% decrease in both over the next several years, thus making sleep-related infant death prevention a national priority.[5]

Newborns hospitalized for illness or prematurity (<37 completed weeks of gestation) fall into an even higher-risk category for sleep-related death. Infants born at 32 weeks' or less gestation die of SIDS at a rate up to 3 times greater than those of term infants; the rates are 2 times greater for those born at 33 to 36 weeks' gestation than for term infants.[6–8]

Similar trends are seen for low birth-weight (LBW) infants (birth weight of <2500 g) when compared with infants of average weights. SIDS mortality is more than 7 times greater for LBW infants when placed in a prone position for sleep.[9] In addition, there are racial and ethnic disparities. Black women, who have a higher rate of preterm birth (13%) than white women (9%), have infants whose rates of SIDS were 83% higher in 2013 than those infants of non-Hispanic white women in 2013.[10]

These findings suggest that SIDS prevention programs are not adequately reaching the highest-risk infants. The 2011 level A recommendations state that all infants in the neonatal intensive care unit (NICU) should be placed in a supine position for every sleep by 32 weeks' postmenstrual age or as soon as they are clinically stable. Despite required SIDS education before discharge, a recent study examining NICU nurses' knowledge, attitudes, and beliefs concerning SIDS RRRs found that NICU nurses do not always believe the SIDS recommendations make a difference in decreasing the rate of SIDS. While the majority of NICU nurses correctly identified 2011 SIDS RRRs, 27% did not place infants in a supine position at the recommended age.[11] This is concerning, as parents have reported mimicking what they see nurses do in the hospital once the infant is home.[12] This observation by parents is a factor identified as a possible explanation for the continued rates of SIDS, the poor adherence to SIDS RRRs by parents, and inconsistent parental practices.[13,14]

Up to 40% of parents do not follow current SIDS RRRs for their infant,[13,15,16] and preterm infants are significantly less likely to be placed in a supine position for sleep than term infants.[14,17] Recent studies of sleep practices of parents of twins[18] and higher-order multiples,[19] the majority of whom were preterm, found that adherence to supine placement for sleep decreased over the first 6 months of life and that less than 50% of the infants shared the sleeping room with their parents. Sharing the same sleep surface, a practice discouraged by the AAP SIDS RRRs, was common for twins (52.2%) and higher-order multiples (29.6%). These findings support the need for SIDS education tailored to the needs of these high-risk infants who are already at a high risk for SIDS, as the presence of additional risk factors (ie, nonsupine sleep) raises the odds of SIDS.[20,21]

A recent review of local, state, and national safe sleep interventions found only 2 prospective randomized trials and none focused on a population of preterm infants. However, programs have been developed for other high-risk populations such as African Americans.[22] Programs found related to improving adherence to SIDS RRRs for preterm infants by improving compliance with care practices in the NICU or education of providers and did not specifically focus on the education of parents concerning these practices postdischarge.[23–25]

It is essential that accurate SIDS RRR information be provided to parents of preterm infants so that they are able to plan how they will care for their infant after discharge. This education should be in a format that facilitates and enhances NICU nurses' provision of this information. No research has been located that examines the effect of an educational intervention tailored for parents of preterm infants on the adherence of mothers to SIDS RRRs and evaluates changes in mothers' plans for caring for the infant and safe sleep practices after discharge as outcomes.

PURPOSE

The purpose of this longitudinal, repeated-measures study was to pilot test an online education module that includes discussion of level A, B, and C SIDS RRRs tailored for parents of preterm infants and to examine changes in mothers' planned practices after discharge.

METHODS

Sample and setting

The setting was a 44-bed single-family room transitional care unit (TCU) in close proximity to the 38-bed level IV NICU. Inclusion criteria were mothers who were 18 years or older, spoke English, retained custody of the infant after discharge, was the mother's first preterm infant, and the mother had access to the Internet after discharge. Infant inclusion criteria were gestational age at birth of less than 37 completed weeks' gestation and projected to be hospitalized for at least 1 week after enrollment in the study. Infants were excluded if it was anticipated that the infant would be discharged home with supplemental oxygen or an apnea monitor.

Intervention

The SIDS education module, "Safe Sleep for Premature Infants," was developed for the purposes of this study

and consisted of 5 sections. The content of first 3 sections reflect level A and level B recommendations based on the AAP 2011 SIDS RRRs: (*a*) Safe Sleep Practices, (*b*) Protective Infant Care Practices, and (*c*) Environment. The fourth and fifth sections (Sleep Promotion & Regulation, and Raising Premature Infants) were included to provide information of interest to parents of preterm infants. The Sleep Promotion & Regulation section includes information on infant sleep requirements and sleep cycles and how to recognize and respond to the infant's signs of sleepiness. The Raising Premature Infants section discusses issues parents face in the first weeks after the infant is discharged, such as the adjustment of family members, including siblings, to having the baby at home. Each section was recorded in Adobe Connect and slides were narrated. The slides include pictures and diagrams to illustrate the points being made. Each section was designed to be a maximum of 10 minutes, allowing 50 minutes for the entire educational module. Mothers are able to choose to watch each section separately or to watch sections together. The first 3 sections of the module are unique, in that rather than simply describing each SIDS RRR (telling the parent what to do), the rationale for the recommendation, based on research evidence, is discussed in lay language. The last 2 sections were developed using lay literature written by healthcare professionals. The content outlines for the module were reviewed by 5 master's and doctorally prepared neonatal nurses, and a script was written for the recording of each section of the module.

Instruments

The Pre- and Post-Discharge Surveys used in the study were adapted from instruments used in previous published work with mothers of preterm and term twins and higher-order multiples.[18,19] The original instruments were developed by the investigators, as no validated instruments existed to assess adherence to the 2011 AAP SIDS RRRs. All 3 instruments included a question asking mothers to rate their knowledge of SIDS RRRs on Likert scale (1-4).

The *Pre-Discharge Survey* is a 43-item questionnaire that asks demographic information, knowledge of SIDS recommendations, and plans for taking care of the infant after discharge. The items in the survey concerning the mother's plans for caring for the baby were developed to reflect level A, B, and C SIDS RRRs. For each item, the choice of responses reflected all possible approaches to care. For instance, concerning the infant's sleep position, mothers were given 3 options as to how the infants would be placed when put to sleep, on their side, back, or stomach. The number of possible options differed between the items. This survey also includes short-answer items.

The *Post-Module Survey* is a 21-item questionnaire designed for the purposes of this study to evaluate the module. It includes questions concerning the length, clarity, and completeness for each section of the module, the time it took to view each section of the module, and whether the mother would change her plans in caring for the infant after viewing the module. This survey includes multiple-choice and short-answer questions.

The *Post-Discharge Survey* is a 37-item questionnaire that updates demographic information and care practices for the infant. The items concerning care practices asked how the infant was being cared for currently, and mothers were asked to choose all that applied. The choices for responses to each item were the same as those in the *Pre-Discharge Survey*.

Procedures

Approval to conduct the study was obtained from University Hospitals Cleveland Medical Center institutional review board. Following an infant's transfer to the TCU at Rainbow Babies and Children's Hospital, the coinvestigator and/or research assistants reviewed the infant's medical chart to assess whether the infant and the mother met the inclusion criteria. If inclusion criteria were met, the coinvestigator or a research assistant approached the infant's mother to discuss enrollment in the study. A mother was given information about the study and given time to decide whether she would like to participate. Once written consent was obtained, mothers were asked to complete the *Pre-Discharge Survey*. After completing the *Pre-Discharge Survey*, mothers were given a choice of viewing the SIDS educational module on an iPad, which was lent to them, or having a link sent via e-mail for them to view on their own computers. Once the SIDS education module was completed, mothers were asked to complete the *Post-Module Survey*. After the *Post-Module Survey* was completed and the iPad returned, mothers received a $20 gift card. At this time, a research assistant arranged to contact the mother via e-mail 4 weeks after discharge to ask her to complete the *Post-Discharge Survey*. When the *Post-Discharge Survey* was returned completed, mothers received a $10 gift card.

Data analysis

Descriptive statistics, including frequency distribution, mean, median, and SD, were used to analyze data. The Wilcoxon signed-rank test was used to measure differences in mothers' rating of their knowledge of SIDS at 3 time points (before viewing the module, immediately after viewing the module, and 1 month after discharge).

Table 1. **Sample demographics (*N* = 15)**

Variable	*n* (%)
Marital status	
Married	6 (40)
Single	9 (60)
Race	
Black	7 (46.7)
White	6 (40)
Asian	1 (6.7)
More than one ethnicity	1 (6.7)
Hispanic/Latino	2 (13.3)
Non-Hispanic/Latino	13 (86.7)
Highest level of education	
Less than high school	1 (6.7)
High school graduate	3 (20)
Some college	6 (40)
Associate degree	1 (6.7)
Bachelor's degree	3 (20)
Graduate school	1 (6.7

RESULTS

Fifteen mothers participated in this pilot study, and 7 of them (46.6%) completed the survey 1 month after discharge. Another mother returned the Post-Discharge Survey uncompleted and indicated her infant had died. The mean age of the mothers was 26.5 years (SD = 6.2), and the infants were born at a mean age of 32.4 weeks of gestation (SD = 1.74; range, 29-35 weeks). Four mothers (26.7%) reported knowing a family member or friend who had a baby die of SIDS. Sample demographics are found in Table 1.

On the Pre-Discharge Survey, 40% of the mothers felt they knew "a little" about SIDS before viewing the modules, and an additional 46.7% felt they knew a "moderate amount." One mother reported knowing nothing, and one knew "a lot." When asked where they had learned about decreasing the risk of SIDS, mothers reported several sources that are found in Table 2.

Table 2. **SIDS knowledge (*N* = 15)**

Where I learned about SIDS risk (all that apply)	*n* (%)
Don't know anything	2 (13.3)
Seeing care in hospital	5 (33.3)
My physician	4 (26.7)
My nurse	5 (33.3)
Friends/relatives	4 (26.7)
Support group	2 (13.3)
TV	3 (20.0)
Baby books/magazines	6 (40.0)

Abbreviation: SIDS, sudden infant death syndrome.

Mothers were asked about the presence of specific risk factors. None of the mothers reported having alcoholic beverages, and one reported smoking 1 to 4 cigarettes a day. Two mothers (13.3%) reported that people in the household smoked.

Plans for caring for baby at home

Ninety-three percent of mothers planned to have the baby sleep in his or her crib, and 86.7% planned to have the baby sleep in the parents' room. When asked where else infants would sleep, mothers reported plans to have the baby sleep in a bassinet (80%), a play pen or portable crib (33.3%), and in Kangaroo Care (20%). Plans for sleep position included supine (86.7%), side (6.7%), and stomach (6.7%). Seventy-three percent of mothers planned to do tummy time once a day. Four mothers (26.7%) planned to use blankets in the baby's crib. No mothers reported plans to use quilts, pillows, or crib bumpers. Plans for other level A and level B recommendations are found in Table 3.

Care practices 1 month postdischarge

Compared with mothers' plans for adherence to SIDS RRRs before discharge, there was a decrease in bed sharing and the use of pacifiers at the time of sleep. Exclusive breastfeeding/provision of breast milk decreased (46.7% planned vs 14.3% providing, respectively) as did sleep location in parents' bedroom (86.7% planned vs 71.4% doing, respectively). Plans for using blankets during sleep did not change 1 month after discharge (26.7% vs 28.6%, respectively). A comparison of planned and actual practices is found in Table 3.

Caring about Preemies' Safe Sleep module evaluation

A Wilcoxon signed-rank test found a statistically significant increase in the mothers' reported rating of knowledge of SIDS RRRs comparing before and immediately after viewing the modules ($Z = -3.140$, $P = .002$) and between before viewing the modules and at 1 month postdischarge ($Z = -2.264$, $P = .024$). Eighty percent ($n = 12$) of the mothers viewed all 5 sections of the module at the same time, and 20% ($n = 3$) viewed the module more than once. Mothers were able to evaluate each section of the module individually in terms of length of time to view the section, the clarity/ability to understand the information, and the completeness of the information. The time for viewing each section of the module ranged from a mean of 8.5 minutes (Protective Practices section) to 11.1 minutes (Infant Sleep Promotion section), with a mean duration of viewing the entire module of 47.8 minutes. The ratings of the length

Table 3. **Adherence to safe sleep practices**

Recommendation	Predischarge plan ($N = 15$), *n* (%)	Postdischarge practice ($N = 7$), *n* (%)
Breastfeeding/provision of breast milk		
Exclusive	7 (46.7)	1 (14.3)
Breast milk and formula	8 (53.3)	4 (26.7)
Formula-only	0	2 (13.3)
Pacifier at time of sleep		
Sometimes	13 (86.7)	4 (57.1)
Most of the time	1 (6.7)	1 (14.3)
Always	1 (6.7)	2 (28.6)
Sleep location		
Parents' room	13 (86.7)	5 (71.4)
Own room	2 (13.3)	2 (28.6)
No bed sharing	14 (93.3)	7 (100))
Sleep position		
On back	13 (86.7)	6 (85.7)
On side	1 (6.7)	1 (14.3)
On stomach	1 (6.7)	0
Keeping baby warm		
Increasing room temperature	7 (46.7)	6 (85.7)
Sleep sack	6 (40)	5 (71.4)
Swaddling	15 (100)	5 (71.4)
Add extra clothing	4 (26.7)	4 (26.7)

of the sections as excellent ranged from 73.3 % (Protective Practices) to 60% (Environment, Sleep Promotion, and Raising Premature Infants). The ratings of the clarity of each section as being excellent were above 80% for all sections, with the exception of the Sleep Promotion section (60%).

Immediately after viewing the modules, mothers reported that the modules contributed to changing their plans for the room in which the baby would sleep (13.3%), the person the baby would sleep with (13.3%), the bed the baby would sleep in (13.3%), the objects in the infant's bed (26.7 %), and the use of a pacifier (53.3%). At 1 month postdischarge, mothers reported that viewing the modules had affected what objects (blankets, toys) would be in the infant's bed (14.3%), the provision of breast milk (28.6%), avoiding the use of alcohol and tobacco (14.3%), and the use of a pacifier (57.1%).

DISCUSSION

This pilot study was the first to evaluate the provision of SIDS education tailored for parents of preterm infants that included explanation of the research evidence for each RRR in lay language, using technology that is readily available to the lay public. In addition, few studies have examined changes in the parents' plans for caring for the preterm infant once the infant was discharged. Consequently, the study provides insight into what recommendations are problematic for parents of preterm infants and this knowledge can be used to further tailor preparation for discharge.

The recommendation to use a pacifier at the time of sleep was the least known SIDS RRR for mothers in this study, most likely because of the avoidance of the use of pacifiers in Baby-Friendly hospitals, including NICUs, due to the perception that pacifier use would interfere with the establishment of breastfeeding. A recent study found that only 36% of nurses in an NICU and TCU identified use of a pacifier at the time of sleep as a SIDS RRR, suggesting that it was not reinforced during discharge teaching.[11] Despite the restriction of pacifier being one of the 10 steps required in Baby-Friendly hospital,[26] the perception that pacifier use would interfere with breastfeeding for term and preterm infants has not been supported.[27–29] It has been recommended that exposure to artificial nipple (pacifiers and bottles) be avoided during the establishment of breastfeeding.[30] After reviewing the module, 53% of the mothers indicated that learning that pacifier use was associated with a decreased risk of SIDS prompted them to change their plans and at 1 month postdischarge, 43% reported offering pacifiers most of the time.

It is concerning that at discharge, 2 mothers (13.35%) had the perception that the infant preferred sleeping on the side or stomach and at 1 month postdischarge

1 infant continued to be placed in a side-lying position for sleep. Side-sleeping adds an additional risk factor, as infants can easily move into a prone sleeping position, putting them at risk for rebreathing exhaled CO_2 and overheating.[31,32] These practices may be related to delays in placing infants in a supine position to sleep at 32 weeks' corrected age as reported by NICU nurses.[11,33] The delay in introducing supine positioning reduces the infant's ability to adapt to that sleep position and reinforces practices the mother will implement at home.

Limitations

The primary limitations of this study are the small sample size and the low return rate 1 month postdischarge. The small sample size was appropriate for the initial piloting of the intervention. The method of data collection at 1 month postdischarge may have contributed to the poor return rate, as it required that the mothers find the time to complete and then return the survey by postal mail. An e-mail 2 weeks postdischarge, to remind mothers that they would be receiving the survey, may have improved the return rate. Other approaches, such as the use of online surveys or telephone interviews,[34] may be more feasible and effective.

Clinical implications

One mother returned the postdischarge survey uncompleted, indicating her infant had died after discharge. While the cause of the infant's death is unknown, a review of the predischarge survey completed by this mother found that she and other family members smoked, indicating that this infant was exposed to an additional significant risk factor for SIDS.[35] The early identification of risk factors in an infant's home presents an opportunity to provide education that is not only tailored for the needs of families of preterm infants but also tailored to address risks specific to that family and expand on basic SIDS RRRs and to promote individualized problem solving as how to reduce risks to their infant.

To be successful, discharge education must be presented in a way that makes it feasible for the nursing staff. One approach using the Caring about Preemies' Safe Sleep (CaPSS) module would be to have the module provided to the mother to view as was done in this study. The nurse could then use "teachback"[36] to determine the mother's understanding of the information and, using the available information concerning risk factors present in the home,[37] spend time with the mother to develop plans for how to implement the SIDS RRR in her home and to anticipate problems.

Research implications

While the mothers' evaluation of the CaPSS module was satisfactory, the feedback indicated areas for improvement. In particular, the section on Sleep Promotion & Regulation was rated lowest on clarity of the content and took the longest time to view. On the basis of this feedback, this section will be revised and the other sections will be reviewed for accuracy and clarity. Ideally, the module will be developed to include interactive opportunities that allow mothers to problem solve. Future research should expand the demographic background of the participants using larger sample sizes and also pilot test the use of the modules as a required component of discharge teaching. Studies should also focus on the education of the family caregivers as well as mothers. It is essential that additional follow-up studies be conducted over longer time frames with larger, more diverse populations to determine when adherence decreases.

In addition, there is a need to better understand the factors that initiate and support parents' decisions to change their intended practices. Studies have reported that parents do not place infants in a supine position to sleep because of a concern for aspiration,[13] infant comfort,[16] occipital head flattening,[38] and the belief that infants do not sleep as soundly on their backs.[13] Understanding how issues, such as the perceived susceptibility of the infant, overcome knowledge of safe sleep practices would inform our approach to educating these mothers.

CONCLUSION

SIDS remains a leading cause of infant death. It is essential that approaches addressing modifiable risk factors, such as sleep position, be developed and tested to improve parental adherence to evidence-based practices that reduce risk. This study was the first to pilot test an intervention aimed solely at mothers of preterm infants to improve adherence to SIDS RRRs by including the research rationale for the recommendations. It was also one of few studies to examine practices of the parents with preterm infants postdischarge. The study found that exposure to the intervention resulted in changes to the parents' plans and that these changes continued over time, as did the parents' perceived knowledge of SIDS RRRs.

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