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Provider and Caregiver perceptions of SIDS/SIUDS prevention in the Black Hills of South Dakota

Levi Franz
University of South Dakota Sanford School of Medicine, levi.franz@coyotes.usd.edu

Kenneth Snell
University of South Dakota Sanford School of Medicine, Kenneth.Snell@Sanfordhealth.org

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Cover Page Footnote

SUIDS are deaths among infants less than one year old, that do not have an immediately obvious cause. The three most common causes of SUIDS are SIDS, Unknown cause and Accidental suffocation and strangulation SIDS is the sudden unexpected and unexplained death of an apparently healthy infant, and is a subset of SUID

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Levi Franz MS-4 and Kenneth Snell M.D.

Introduction

Despite medical advancements, infant death rates in the US remain elevated compared to many European countries [1]. The rate of neonatal mortality in the US and European countries are similar, implying that much of the infant death rate discrepancy is due to deaths occurring later in infancy. According to one study, the number of infants who die each year could be reduced from 7000 to less than 3000 with better mitigation of all causes of infant mortality, with Sudden Unexpected Infant Death Syndrome [a] (SUIDS) being the area where the most significant gains are possible [1]. Infant mortality rates caused by Sudden Infant Death Syndrome[b] (SIDS) have been decreasing since the start of the 1994 "Back to Sleep" campaign which works to educate caregivers on the importance of a supine sleeping position. In spite of this, deaths from SUIDS have continued to climb [2]. This increase is likely due to an increase in unsafe sleep environments, especially adult caregivers sharing beds with infants (co-sleeping) [2].

South Dakota as a state has rates of SIDS and SUIDS that are three times those of US states with the lowest rates [1]. For comparison, even the states with the lowest SIDS/SUIDS rates were still higher than the highest performing European countries. According to the Infant Death Review published in 2016, only 5 states had higher rates of infant death than South Dakota in 2015 [3]. Of all causes of infant mortality, sleep related deaths accounted for 60% of infant deaths outside of the hospital, and before the child's first birthday, between 2013-2016 [3].

Education of parents on reducing the risk of SUIDS/SIDS has been shown to have mixed results in preventing SUIDS/SIDS. One study found that several standardized follow up telephone education sessions did not improve rates of supine sleep position among African American mothers [4]. However, the utility of education can be drawn from the success that the "Back to Sleep" educational campaign had in reducing rates of SIDS, which saw rates of SIDS drop by nearly 50% between 1994 and 2004 [2]. Additionally, previous studies have suggested that physician input is the most significant factor affecting whether or not an infant is placed in a supine sleeping position [5]. Many sources of information regarding SIDS and SUIDS exist, and few studies have compared the efficacy of any of these sources.

This study aims to better equip physicians and health officials in their educational campaigns and caregiver interactions. This is accomplished by evaluating the compliance of caregivers to safe sleep guidelines relative to their information sources regarding SIDS/SUIDS, assessing physicians' assumptions of caregiver knowledge of SIDS/SUIDS and then comparing that to actual caregiver compliance, and determining which topic related to SIDS/SUIDS that caregivers are least compliant with.

Methods

Study Design

This was a descriptive study conducted through the use of surveys at a single pediatric clinic during the month of February 2019. Surveys were developed from a 2019 National Institute of Health (NIH) brochure[6] covering common SIDS topics, which contained information about safe sleep practices that is readily available to caregivers. The patients of the clinic are the infants being cared for by caregivers. The term "caregiver" will be used for the person responsible for the infant. Response to a survey item was termed "compliant" if that choice was consistent with NIH safe-sleep guidelines, and "non-compliant" if that choice did not comply with the

[a] SUIDS are deaths among infants less than one year old, that do not have an immediately obvious cause. The three most common causes of SUIDS are SIDS, Unknown cause and Accidental suffocation and strangulation

[b] SIDS is the sudden unexpected and unexplained death of an apparently healthy infant, and is a subset of SUID

guidelines. In total, 300 surveys were distributed to caregivers by front desk staff during their check-in process. Of these, a total of 198 surveys were returned to a locked drop box that was placed in the reception area of the clinic. Surveys were disbursed following approval by the University of South Dakota Institutional Review Board. Selection criteria for inclusion in the survey were that respondents be at least 18 years old, and the caregiver of a 0 to 9-month-old child.

Caregivers were asked to rate their own knowledge of SIDS on a 1-10 scale prior to completing the surveys. They were also asked to circle the most significant source of their knowledge about SIDS. Caregivers were given the option to choose from one of the following: “family member”, “physician/nurse”, “online resource”, “pamphlet/handout”, “social media” or “unknown”. An example survey can be seen in Appendix A. Results to this question were used to examine the relationship between sources of caregivers’ information on SIDS risk reduction, and their compliance with the NIH safe sleep guidelines.

Prior to survey distribution to caregivers, a single related survey was distributed to the physicians at the clinic. A total of 5 of the 6 pediatricians were surveyed. These surveys asked the physicians to predict the percentage of their caregiver populations that were reporting caregiving behacior with their infants that is compliant with NIH guidelines.

Following survey collection, data were entered into a Microsoft Excel spreadsheet for analysis. Case information included information source(s) from which caregivers obtained SIDS/SUIDS information, and responses to all of the safe-sleep items, which indicate reported caregiver behaviors with regard to care of their infant. The percent compliant score was calculated from these data.

Following these calculations, the physician estimation of “compliant” responses was compared to caregiver mean “compliant” responses. In order to determine the effect of the different information sources, analysis of Variance (ANOVA) was run on the 12 items.

Results

The caregiver estimate of their own knowledge of SIDS was first correlated with number of compliant responses on the surveys. This correlation was found to be 0.184 with a p-value of .0101. This suggests that there is a statistically significant relationship between caregiver belief in their own knowledge and objective result. However, this relationship is weak and likely not clinically relevant.

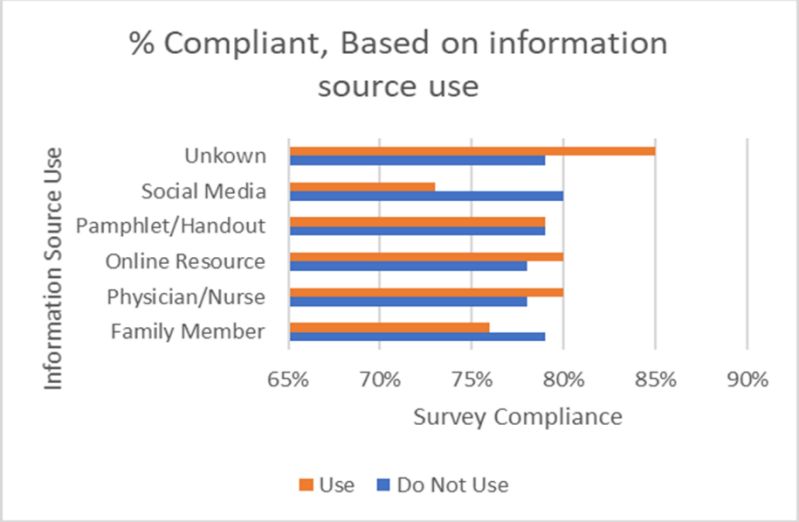

Figure 1: Precent compliant based on whether information sources were reported as used to inform caregivers regarding SIDS/SUIDS

The 6 sources of information were next checked to determine if these were related to percent “compliant”. Differences were small for all sources but for those who included a response of “Social Media” or “Unknown”. “Unknown” had a slightly higher mean compliant compared to the other responses. There was a higher level of percent compliant for those who did not cite “social media”. The significance of these results was examined with ANOVA. Results of the analysis are presented in Figure 1. A response of “social media” was statistically significant, with those who did report it as a source scoring an average of 73% compliant, and those who did not report it as a source scoring an average of 80% compliant. This

difference had a p-value of 0.0169. No other sources of information had a significant impact on the respondents' percentage of compliant responses.

Comparisons of the physician predictions of caregiver responses and the reported behaviors of caregivers showed two significant differences. These were the questions regarding secondhand smoke exposure and crib ownership, for both of these issues, physicians underestimated the level of compliance. The p-values for both of these questions were <0.0001.

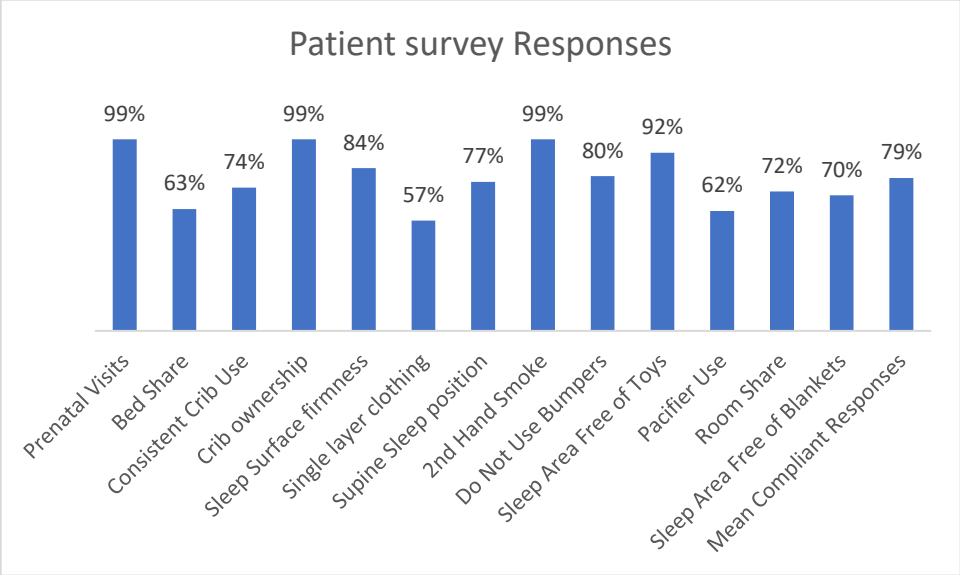

Figure 2: Average percent compliant with NIH guidelines per survey question, as reported by caregivers

Analysis of the respondents answers for given questions reveals that the topics for which caregivers were most frequently compliant were whether caregivers had seen a physician during their pregnancy (99%), owned a crib or bassinet (99%) or avoided second hand smoke in the home (99%). Analysis of caregiver reports of behaviors that are non-compliant with NIH guidance about safe sleep show that caregivers are likely to over bundle their child (43%), not use a pacifier (38%) and bed share (37%). Responses to answers are summarized in Figure 2.

Discussion

Physician input on correct sleep position has been shown to be influential in caregivers' decision regarding supine sleep position[7]. Pediatric providers, however, have short visit times, and high volumes of patients to see each day. These time restrictions make it difficult for providers to provide education on every potential topic. Because of this, it is important to be able to prioritize which educational topics they discuss with a given caregiver.

Provider probing regarding the source of caregiver's information sources regarding SIDS and SUIDS may serve as an indicator of the patient's level of compliance with NIH guidelines. Studies have shown that false information spreads at a significantly faster rate on social media than does factual information [8] The data show that those who used social media as a source of information on risk reduction for SIDS had significantly lower compliance on NIH guidance than did those who did not use social media. Therefore, caregivers who report that social media is a significant source of information likely require more education regarding SIDS/SUIDS. This is an aspect of SIDS/SUIDS education where a more robust online presence by the State of South Dakota Department of Health and pediatric clinics could help to combat the large amount of incorrect information available.

The results of the caregiver survey can help guide physician conversations with caregivers. Survey results showed that the SIDS/SUIDS topics that were best understood by caregivers were with relation to secondhand smoke exposure (99% compliant) and owning a crib (99% compliant). Ownership of a crib did not necessarily equate to use of a crib, as 24% of respondents reported not using a crib consistently, and 37% reported bed sharing. From

this it appears that providers should not ask whether or not caregivers own a crib, but more specific questions about where the infant actually sleeps most nights. Pacifier use (57% compliant) and over bundling (57% compliant) were the least understood. Of note, bed sharing was reported among 38% of respondents, indicating an area where significant improvement is possible. Thornhill-Scott et. al found that physicians who see new parents in Kansas tended to spend a majority of their SIDS education time counselling parents on limiting second hand smoke exposure and sleep position, with little time spent on pacifier use and mattress type [9]. If the results from the study were extrapolated to Western South Dakota, it would appear as though physicians are spending more time educating caregivers on topics that they understand well, such as secondhand smoke exposure. Additionally, poorly understood topics, such as pacifier use, are not receiving appropriate time. This same study showed that physicians were least informed of pacifier use as a means of decreasing the incidence of SIDS, which could account for this discrepancy, as physicians would be less willing to engage in a discussion of a topic they do not understand well [9]. From this, it appears that the knowledge of pacifier's preventative utility is not well known among providers or care takers, and efforts likely need to be undertaken at the national and state levels to better educate physicians of the NIH guidelines regarding their use.

The difference between the physician predicted responses, and the actual results of the survey was not statistically significant for the majority of survey items. One possible conclusion to be drawn, is that physicians are adept at predicting the overall knowledge base of their caregiver populations. Of the 12 items on the survey, the physician predicted responses differed from the actual responses by a statistically significant margin for two of the questions. Those questions were those with regard to secondhand smoke exposure and owning a crib. It is possible that the social stigma surrounding these two questions could potentially represent a statistical anomaly in which caregivers are aware of the right response, and thus do not answer honestly, feeling shame in spite of the anonymous nature of the surveys. Most caregivers would likely be hesitant to admit to exposing their child to secondhand smoke, or not providing their child with appropriate sleep environments. There is also a possibility that physicians are able to smell smoke on their caregivers' clothes and may have a more honest view of this question than our survey respondents were willing to disclose. Regardless of the reasons for this discrepancy, discussing the importance of limiting second hand smoke exposure or crib ownership may not need to be a priority if time is limited. These topics are likely still important to discuss, as our survey did not ask patients whether they knew about the connection between second hand smoke exposure and SIDS.

Conclusion

Several limitations to this study exist. The most significant issues stemmed from the SARS-CoV-19 Pandemic. This event limited the number of surveys that were distributed, as other clinics refused to distribute surveys due to this event. Only 5 physician surveys were returned, which significantly decreased the statistical power of the study. An additional limitation of the study was that the caregiver questionnaire asked that caregivers circle the most significant source of information, allowing only one response. However, a large portion of respondents circled more than one information source. Because of this, all responses were included in the final analysis. A similar electronic questionnaire that only allowed for a single response, or a paper questionnaire that allowed for multiple responses could be redone in the future for more accurate results. Alternatively, the question could be phrased to ask "Circle all important sources of information".

This study did show that there was a correlation between caregivers perceived expertise regarding SIDS/SUIDS and their actual knowledge, however this correlation was weak, indicating that physicians should not take caregivers at their word when they say that they understand safe sleep.

There is significant opportunity to decrease the high rate of sleep related infant deaths in South Dakota. Areas of educational need include pacifier use and bed sharing. Of these, pacifier use, has been shown to be a poorly

discussed topic in other states. Physicians should also feel free to limit discussions regarding secondhand smoke exposure and owning a crib, as caregiver populations demonstrated excellent knowledge of these principles.

Opportunities for improved education also exist among caregivers who report social media as a significant source of information regarding SIDS and SUIDS. Combating incorrect information found on social media sites is something that providers and State officials can utilize to decrease the number of infant deaths.

Neither author has any conflicting interest with regards to this research.

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Appendix A: Caregiver sleep survey

Patients' Sleep Survey

(Answer questions only about your child aged 0-9 months)

1. By Checking this box, I certify that I am 18 years or older: □
2. On a scale of 1-10, with 1 being very little, and 10 being a great deal, how well would you rate your knowledge of Sudden Infant Death Syndrome: (1-10) _____
3. Where do you get most of your information regarding Sudden Infant Death Syndrome (please circle one)?
    a. Family Member
    b. Physician/Nurse
    c. Online resource
    d. Pamphlet/handout
    e. Social Media
    f. Unknown
4. Did the child's mother regularly see a physician during the pregnancy?
    a. Yes
    b. No
5. Does your baby ever sleep in the same bed as an adult or sibling?
    a. Yes
    b. No
6. Where does your baby sleep most nights (please circle one)?
    a. Adult bed
    b. Crib
    c. Couch
    d. Recliner
    e. Floor
    f. Car Seat
    g. Swing
    h. Other: _____
7. Do you have a safe crib, Portable crib or bassinet at your home?
    a. Yes
    b. No
8. Compared to an adult bed, how would you describe your baby's sleep surface (please circle one)?
    a. Harder
    b. sleeps in adult bed
    c. Softer
9. How many layers does your baby sleep in at night (Counting a sleeper, or clothing, but not a diaper)?
    a. 1
    b. 2 or more
10. What position does your baby sleep in most nights (circle one)?
    a. back
    b. stomach
    c. side
11. Does anyone smoke inside your house?
    a. Yes
    b. No
12. If you use a crib, does it have bumper pads?
    a. Yes
    b. No
13. Does your baby sleep with toys or stuffed animals in their bed?
    a. Yes
    b. No
14. Does your baby use a pacifier?
    a. Yes
    b. No
15. Does your baby sleep in the same room as their adult caregiver?
    a. Yes
    b. No
16. Does you baby sleep with blankets in the crib?
    a. Yes

b. No

Appendix B: Physician survey

Safe Sleep Physician Survey

1. What is your medical specialty?
   Family Physician Pediatrician OB/GYN Other: _____
2. How often do you see patients aged 0-9 months?
   Very often Often Occasionally Rarely Very Rarely
3. How frequently do you talk with the family of your patients about SIDS?
   Very Often Often Occasionally Rarely Very Rarely

Sleep Survey Predictor

(Answer questions only with regard to patients aged 0-9 months)

1. How informed are most of your patients with regards to SIDS on a 1-10 scale (1 is very little and 10 is a great deal)? _____
2. What percentage of your patients would you say have regular prenatal care prior to delivery?
   Unknown 0-25% 26-50% 51-75% 76-100%
3. What is the most significant source of SIDS information for your patient population?
   a. Family Member
   b. Physician/Nurse
   c. Online Resource
   d. Pamphlet/handout
   e. Social Media
   f. Unknown
4. What percentage of your patients co sleep?
   Unknown 0-25% 26-50% 51-75% 76-100%
5. What percentage of your patient population has their babies sleep in a crib most nights?
   Unknown 0-25% 26-50% 51-75% 76-100%
6. What percentage of your population owns a safe crib, portable crib or bassinet?
   Unknown 0-25% 26-50% 51-75% 76-100%
7. What percentage of your population sleeps on a surface that is softer than it should be?
   Unknown 0-25% 26-50% 51-75% 76-100%
8. What percentage of your patients over bundle their babies at night?
   Unknown 0-25% 26-50% 51-75% 76-100%
9. What percentage of your patients put their babies to sleep on their back at night?
   Unknown 0-25% 26-50% 51-75% 76-100%
10. What percentage of your patients are exposed to secondhand smoke in their home?
    Unknown 0-25% 26-50% 51-75% 76-100%
11. What percentage of your patient population uses bumpers in their cribs?
    Unknown 0-25% 26-50% 51-75% 76-100%
12. What percentage of your patient population sleeps with toys or stuffed animals in their sleep area?
    Unknown 0-25% 26-50% 51-75% 76-100%
13. What percentage of your patient population uses a pacifier?
    Unknown 0-25% 26-50% 51-75% 76-100%
14. What percentage of your patient population sleeps in the same room as their caregiver?
    Unknown 0-25% 26-50% 51-75% 76-100%
15. What percentage of your population sleeps with blankets in the crib?
    Unknown 0-25% 26-50% 51-75% 76-100%