

Sudden Infant Death Syndrome Awareness in Relation to the Perceptions of African American Women

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Introduction/Background

Sudden Infant Death Syndrome is a diagnosis given to an infant that has suddenly died unexpectedly (2). The risk of SIDS is more prevalent in the ages of two to four months during sleeping (2). Although the cause of SIDS is not clearly understood, it is suggested that some of the characteristics associated with the syndrome interact with each other and has been given the name of triple-risk model. Triple risk model proposes that SIDS occurs when a vulnerable infant is exposed to an outside stressor during the critical age (5). SIDS also been known to affect perfectly healthy infants as well.

Although SIDS affects all communities African American infants are twice as likely to be affected compared to their White counterparts (4). While there has been a decrease in the number of SIDS deaths, Mississippi is still above the national average in SIDS cases (3). Several organizations in Mississippi have taken initiative to educate mothers and caregivers on reducing infants' risk of SIDS, but there is still a need for more education and awareness in reference to SIDS in order to understand different perceptions and beliefs concerning SIDS.

The objectives of my project were to:

1. Evaluate each patient's current knowledge as it is related to SIDS and how it affects decisions correlated to SIDS.

2. Provide patient's with information on: what SIDS is, what causes SIDS, and recommendations to help reduce the risk of SIDS.
3. Discuss with patients the importance of following the recommendations to reduce SIDS.
4. Evaluate if the clinics provided any educational assistance to patients on SIDS.

Methodology

Patients who identify as African American and who were between the ages of 18-66 were asked to participate in this study. Each patient was read the following informed consent process script:

“My name is Fanshon Montgomery and I am a second year medical student working on a research project regarding Sudden Infant Death Syndrome. We want to know what people already know about SIDS and how it affects what they do. Your participation in my study is voluntary, and will take about 10-15 minutes before or after your visit today. If you decide to participate, you can stop at any time during the process. I will ask you some questions or you will answer some questions on this form. We will review a Sudden Infant Death Syndrome presentation and then discuss any questions or comments you may have. No personal information will be tied to any of the surveys to be able to identify who you are. There are no known risks to participating. The benefit may be that we will learn how to educate patients better about SIDS. Would you like to participate?”

Each patient was given a pre-survey to fill out before an informative presentation regarding SIDS. The pre-survey contained 12 questions that were placed into four different categories:

A. Previous Learning:

1. Have you ever heard of Sudden Infant Death Syndrome (SIDS)? Yes or No
2. What do you think causes SIDS?
3. Do you know what constitutes a safe sleeping environment? Yes or No If so, what?
4. While sleeping, should a child be placed on his stomach, side, or back?

These three questions were intended to provide a qualitative assessment of patient's previous knowledge on the subject of Sudden Infant Death Syndrome.

B. Previous Experience:

1. Have you had/Did you have any discussion on SIDs with any of your physicians or healthcare providers at Central Mississippi health Services while you were pregnant? Yes or No Other locations?
2. Have you seen or heard any SIDS prevention messages in your community? Yes or No
3. Do/Did you co-sleep with your child? Yes or No

These questions were intended to provide a qualitative assessment of patient's previous experiences with Sudden Infant Death Syndrome and to assess if that previous experience would affect how the patient viewed SIDS.

C. Attitudes and Interest

1. Do you think that African Americans are at greater risk than any other race?

Yes or No

2. Do you think that you can do anything to try to prevent SIDS from happening? Yes or No If so, what? If not, why?

These questions were intended to provide a qualitative assessment of patient's attitudes/interest concerning Sudden Infant Death Syndrome.

D. Needs and Feelings

1. In general, how effective would you say SIDS prevention messages and educational campaigns are in educating the African American community?

Very effective, somewhat effective, or not at all effective.

2. In general, would you say that SIDS is a major problem, a minor problem, not a problem at all in the community? Or I don't know

3. Are/ Were you concerned that SIDS can happen to your child? Yes or No If not, why?

These questions were intended to provide a qualitative assessment of patient's needs/feelings regarding Sudden Infant Death Syndrome.

After filling out the pre-survey, each patient will have a chance to view the Sudden Infant Death Syndrome presentation adopted from the Resource Kit for Reducing the Risk of Sudden Infant Death Syndrome in African American Communities from the Back to Sleep campaign released by the American Academy of Pediatrics (1) that included; what SIDS is, the cause of SIDS, what myths/ facts regarding SIDS, and what can be done to reduce the risk of SIDS. After

the presentation, participants engaged in dialogue in order to ask questions and discuss their viewpoints. Many of the patients engaged in dialogue during the Sudden Infant Death Syndrome presentation once they heard something that they did not know or did not agree with. After the open discussion each patient took a post-survey.

The post survey had five questions that were also placed in the above four categories.

1. Do you think that any of the SIDS recommendations have an impact on how you care/ will care/did care for your child? Yes or No (d)
2. Did you follow any of the recommendations before the presentation? Yes or No (b)
3. Was there a recommendation that you weren't following that you are willing to follow now? Yes or No If, so which one? If not, why? (c)
4. How likely are you to discuss this information with your physician, healthcare provider, a family member, or friend? (More than likely, somewhat likely, not likely) If not likely, why? (d)
5. Did you find this information helpful? Yes or No (c)

Results

Over a two week period, I was able to interview 35 women between the ages of 18-66 at the Central Mississippi Health Services Winter St. and Robinson Rd ext. location. Of the 35 women, only one patient was currently pregnant and only one patient had just recently had a child that was less than one year old. Six of the 35 women reported that they did not have any children.

The following tables under each question/perception category give the age ranges and how many patients answered and how they answered.

A. Previous Learning:

1. Have you ever heard of Sudden Infant Death Syndrome (SIDS)? Yes or No

	18-24	25-31	32-38	39-45	46-52	53-59	60-66
Yes	1	3	6	4	2	6	6
No	4	0	1	0	1	0	0

2. What do you think causes SIDS?

3. Do you know what constitutes a safe sleeping environment? Yes or No If so, what?

	18-24	25-31	32-38	39-45	46-52	53-59	60-66
Yes	2	3	6	3	3	6	5
No	1	0	1	1	0	0	2

4. While sleeping, should a child be placed on his stomach, side, or back?

	18-24	25-31	32-38	39-45	46-52	53-59	60-66
Stomach	1	0	2	0	0	2	2
Side	0	0	0	2	2	1	1
Back	4	3	5	2	1	3	3
I don't know	0	0	0	0	0	0	1

B. Previous Experience

1. Have you had/Did you have any discussion on SIDs with any of your physicians or healthcare providers at Central Mississippi health Services while you were pregnant? Yes or No Other locations?

	18-24	25-31	32-38	39-45	46-52	53-59	60-66
Yes	1	1	5	3	1	1	5
No	0	2	1	1	2	5	0

2. Have you seen or heard any SIDS prevention messages in your community? Yes or No

	18-24	25-31	32-38	39-45	46-52	53-59	60-66
Yes	0	0	4	1	0	1	2
No	5	3	3	3	3	5	5

3. Do/Did you co-sleep with your child? Yes or No

	18-24	25-31	32-38	39-45	46-52	53-59	60-66
Yes	0	2	6	3	3	4	4
No	1	0	1	1	0	2	3

C. Attitudes and Interest

1. Do you think that African Americans are at greater risk than any other race? Yes or No

	18-24	25-31	32-38	39-45	46-52	53-59	60-66
Yes	1	2	3	0	0	0	1
No	1	0	2	4	3	4	5
I don't Know	0	1	0	0	0	2	0

2. Do you think that you can do anything to try to prevent SIDS from happening? Yes or No If so, what? If not, why?

	18-24	25-31	32-38	39-45	46-52	53-59	60-66
Yes	0	3	5	1	1	5	2
No	1	0	1	3	1	1	5

D. Needs and Feelings

1. In general, how effective would you say SIDS prevention messages and educational campaigns are in educating the African American community? Very effective, somewhat effective, or not at all effective.

	18-24	25-31	32-38	39-45	46-52	53-59	60-66
Very Effective	0	0	1	0	0	1	1
Somewhat Effective	1	0	3	4	1	0	1
Not at all Effective	0	3	3	0	1	3	4
I don't Know	0		0	0	1	2	1

2. In general, would you say that SIDS is a major problem, a minor problem, not a problem at all in the community? Or I don't know

	18-24	25-31	32-38	39-45	46-52	53-59	60-66
Major Problem	1	2	3	2	1	2	4
Minor Problem	0	1	3	1	1	1	2
Not a Problem at all	0	0	0	0	0	1	0
I don't Know	0	0	1	1	1	2	1

3. Are/ Were you concerned that SIDS can happen to your child? Yes or No If not, why?

	18-24	25-31	32-38	39-45	46-52	53-59	60-66
Yes	1	1	4	2	1	4	2
No	0	0	3	2	2	2	5

Discussion

The results show that that mother's awareness, perceptions, and practices may have room for improvement. During the surveys there were a couple of observations that were made that need to be discussed. The population sample was too small. It would have been nice to have at least 20 surveyed in each age range, so that there would be a better analysis of the data collected.

In the age range of 18-24, the answers to the surveys will be vague because only one of them had had a child and heard of SIDS before. It was surprising that the younger patients that were surveyed had not heard of Sudden Infant Death Syndrome and more of the older patients had. Since the younger patients hadn't heard of Sudden Infant Death Syndrome, they were not able to answer a majority of the question on the pre-survey. There were some older patients who said they had not heard of SIDS before, but once they viewed the presentation and realized that

SIDS was also known as crib death they would say that they had heard of SIDS. It was called crib death when they were younger. The choice of using SIDS instead of crib death on the survey may have distorted the older patients' answers for choosing the answer choice no to the question.

Most of the patients surveyed responded that they had not had any discussion with their physician or healthcare provider at Central Mississippi Health Services or at any other location. I do believe that there were so many patients who answered no to that question because the surveyed population was much older and had older children and grandchildren. There were comments made stating "No. I didn't, but I'm not sure" and "It was too long ago. All of my children are grown." Many of them may have had discussion with their physicians, but just could not remember.

Something else that needs to be pointed out is the fact that many surveyed responded yes to having heard of SIDS before, but once asked what caused SIDS or any other questions regarding the subject, many of them could not explain anything. They would comment with "I just don't know." I think this is because many of them did not want to say that they had not heard of SIDS and for the ones who had heard of SIDS and could not explain answer questions concerning SIDS it was due to a lack of education in the community.

Most of the patients surveyed responded that African Americans are not at greater risk than any other race. During the discussion, many had only heard of White babies dying from SIDS or only seen White individuals on commercials advertising SIDS. Some felt that it was not a true statistic and offered their reasons why. During the discussions, we talked about how many of the African American mothers do not follow the recommendations that are out there in order to reduce SIDS cases. We also talked about socioeconomic status. Many in the African American community are living below the poverty line. Many of the mothers cannot afford to buy a crib for

the baby to sleep in, so the baby must sleep in the bed with them. Instead of being told that they suffocated their child, the child is labeled as a SIDS case. A lot of factors came into play when discussing that question.

The last question that I want to discuss from the survey is that many people did know that an infant should be placed on his/her back, but refuse to follow that recommendation. They were concerned that the baby would choke on his/her spit. It was also a recurring theme that my mother or grandmother never placed her baby on his/her back and we all turned out fine. If it worked for her then it will work for me. It was generations after generations passing down information that was obsolete now and many were not willing to change.

Recommendations

I have two recommendations that Central Mississippi Health Services (CMHS) can do to make sure that they are doing their part in educating the African American community and surrounding areas. First, CMHS can make sure that the providers are discussing SIDS with the pregnant patients and the patients that just had a child during their prenatal visits. One talk can be at seven months and the other can be once they come back to see the physician after they have had the baby. Second, CMHS can have literature and posters at their South clinic since that is where the Women's Wellness visits are held. If a future scholar was to repeat this study, I would suggest that they try to target women who are between the ages of 16-35 and women who are pregnant or who have just had a baby.

Conclusion

In conclusion, the patient's knowledge regarding Sudden Infant Death Syndrome was limited and their perceptions played a huge part in their willingness to follow recommendations to decrease an infant's risk of dying from SIDS. It was shown that mother's awareness,

perceptions, and practices may have room for improvement. The next step would be for the physicians to take an active role in discussing Sudden Infant Death Syndrome with patients, so that the number of SIDS cases can be reduced in Mississippi.

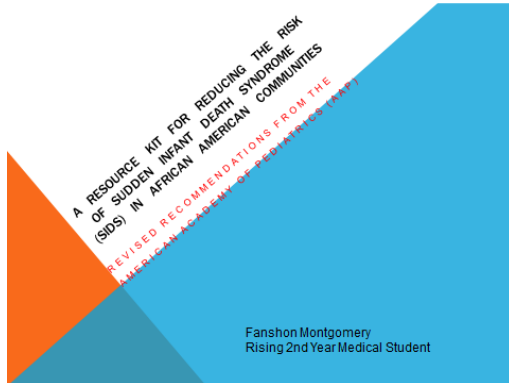
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Appendix A

The following is the PowerPoint presentation used to educate the patients on Sudden Infant Death Syndrome.



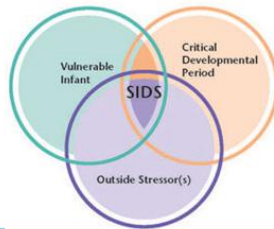
WHAT IS SUDDEN INFANT DEATH SYNDROME?

- The sudden and unexpected death of an infant younger than 1 year of age for which no exact cause of death can be determined.
- Because most SIDS deaths occur while infants are sleeping in a crib, SIDS is commonly referred to as “crib death.”

WHAT CAUSES SUDDEN INFANT DEATH SYNDROME?

Unknown Cause

Triple Risk Model



SUDDEN INFANT DEATH SYNDROME MYTHS/ FACTS

- Babies can “catch” SIDS.
- Cribs cause “crib death,” or SIDS.
- Babies who sleep on their backs can choke on spit or vomit.
- Only white babies die of SIDS.
- SIDS cannot be caught.
- Cribs do not cause SIDS.
- Babies swallow or cough up fluid that enters their airway. Doctors have found no increase in choking or other problems in babies sleeping on their backs.
- African American babies are twice as likely to die of SIDS as white babies

SUDDEN INFANT DEATH SYNDROME MYTHS/ FACTS

- A SIDS death can be prevented.
- Shots or medicines cause SIDS.
- SIDS can occur at any age.
- Although there is no way to make sure a baby will not die of SIDS, the chance of a baby dying of SIDS can be greatly reduced by placing babies on their backs to sleep
- Shots or medicines do not cause SIDS. All babies should be seen for well baby checkups. Babies should also receive their shots on time.
- SIDS is the unexplained death of a baby younger than 1 year of age. Most SIDS deaths happen between 2 and 4 months of age. The number of babies dying of SIDS dramatically drops after 6 months of age.

ACTIONS TO REDUCE THE RISK OF SIDS

- Always place your baby on his or her back to sleep, for naps and at night. The back position is the safest
- Place your baby on a firm sleep surface, such as on a safety approved crib mattress, covered by a fitted sheet. Never place your baby to sleep on pillows, quilts, sheepskins, or other soft surfaces.
- Keep soft objects, toys, and loose bedding out of your baby's sleep area. Don't use pillows, blankets, quilts, sheepskins, or pillow-like crib bumpers in your baby's sleep area, and keep all other items away from your baby's face.

ACTIONS TO REDUCE THE RISK OF SIDS

- ◆ **Do not allow smoking around your baby.**
Don't smoke before or after the birth of your baby, and don't let others smoke around your baby.
- ◆ **Keep your baby's sleep area close to, but separate from, where you and others sleep.**
Your baby should not sleep in a bed or on a couch or armchair with adults or other children, but he or she can sleep in the same room as you. If you bring your baby into bed with you to breastfeed, put him or her back in a separate sleep area, such as a bassinet, crib, cradle, or bedside cosleeper (infant bed that attaches to an adult bed) when finished.
- ◆ **Think about using a clean, dry pacifier when placing the infant down to sleep.** But don't force the baby to take it. (If you are breastfeeding your baby, wait until your child is 1 month old or is used to breastfeeding before using a pacifier.) the baby can slip under the blanket.

ACTIONS TO REDUCE THE RISK OF SIDS

- ◆ **Do not let your baby overheat during sleep.**
Dress your baby in light sleep clothing, and keep the room at a temperature that is comfortable for an adult.
- ◆ **Avoid products that claim to reduce the risk of SIDS because most have not been tested for effectiveness or safety.**
- ◆ **Do not use home monitors to reduce the risk of SIDS.**
If you have questions about using monitors for other conditions talk to your health care provider.
- ◆ **Reduce the chance that flat spots will develop on your baby's head:** provide "Tummy Time" when your baby is awake and someone is watching; change the direction that your baby lies in the crib from one week to the next; and avoid too much time in car seats, carriers, and bouncers.

GOOD HEALTH CARE HELPS REDUCE MANY RISKS

- ◆ **Much of what you probably do now to protect your baby's health also reduces the risk of SIDS.**
- ◆ **Get good health care before and during pregnancy.**
- ◆ **Breastfeed your baby if possible.**
- ◆ **Take your baby for scheduled well-baby checkups and shots.**

QUESTIONS???

REFERENCES

1. A Resource Kit for Reducing the Risk of Sudden Infant Death Syndrome (SIDS) in African American Communities. (2006, March). Retrieved from https://www.nichd.nih.gov/publications/pubs/documents/SIDS_resource_kit_rev.pdf