

A summary of the interactive workshop with Rachel Moon, M.D. at the International Conference on Perinatal and Infant Death

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National SUID/SIDS Consortium

Providing resources to states, communities, professionals, and families to reduce SUID/SIDS and promote healthy outcomes

> SUID/SIDS Resource Center Project IMPACT Program Support Center National Center for Cultural Competence

Hot Topics in Infant Safe Sleep

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Association of SIDS and Infant Mortality Programs and Pregnancy Loss and Infant Death Alliance:

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This interactive session was designed to help participants use the latest research in their practice settings. Participants were divided into 6 groups. Each group was given a scenario of a situation related to safe sleep that they might encounter in practice. Groups were asked to discuss the following:

- What would your advice be?
- How comfortable are you with this advice?
- What is your understanding of the research and evidence supporting your advice?
- What questions do you have about the research and evidence?

The following notes summarize the reports from the groups and the discussions with Dr. Moon related to current research.

Scenario 1: You are conducting a home visit at the home of a family with a 2 month old infant. The mother reports that the infant has been diagnosed with reflux. She is placing the baby on the stomach, because she's worried that he's going to choke. She was also told that she should keep him upright after he eats, so sometimes he sleeps in his car seat.

How would you handle the scenario?

We would start off by asking the family about the source of their information. Where did you hear that? Was it from the doctor, friends, family, mother? Even if the information was from the doctor, we would talk about the fact that the latest research shows that even for babies with reflux, supine sleep is recommended. The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (the experts on pediatric gastroesophageal reflux) discourages people from putting babies to sleep on the stomach. Tell them about those official guidelines. We think it is very effective to use visuals of how baby breathes on the stomach vs. back and how aspiration is more likely on the stomach. We have found that very useful. Also we would normalize reflux — all babies spit up. Ask them if they think this is normal. One major cause of spitting up is overfeeding so this is also a chance to talk about feeding practices.

We also talked about the issue of the car seat. The child is sitting at a different angle when the car seat is in the car. We would ask the mother questions to find out "What is going on in her life?" — but tell her that the baby should not be in the car seat when it is not in the car.

The groups wondered about: What is latest research about angling the crib up?

Finally, we would ask mother about her concerns — if the baby sleeps better on his stomach, how can you get support for change in the baby's sleep patterns?

Group Discussion:

- The group seems to be assuming that the baby is bottle fed, but if breastfed, check the mother's diet. If bottle fed, have they tried any other formulas?
- Is this a first baby? Or, if not, how did mother place her other babies for sleep?
- Was the baby a preemie?

Current Research Related to Scenario 1

Fear of choking/aspiration

People typically describe choking as coughing, spitting, sputtering. In fact, these are part of the normal gag reflex, not choking. The baby is keeping himself from choking and aspirating. It is important to help families understand this point.

Reflux

First, define reflux — the contents of stomach coming up into the mouth — spit up, burping, etc. When do we need to worry about reflux? 1) If it is projectile, (could be a sign of some other problem, such as pyloric stenosis); 2) if there is more coming out than going in (in which case the baby should not be gaining weight); 3) when it's painful and they cry (acid reflux). Of the kids who have reflux, 99% are "happy spitters". It's messy, but the baby is fine. In general, if the baby is gaining weight, the baby is fine.

Then you need to address parental worry about supine position and reflux/choking. We need to explain and show the relative positions of the trachea and esophagus. When the baby is supine, food comes up the esophagus, but the trachea is on top of the esophagus, so food has to go up against gravity. If on the stomach, the trachea is below, so if the baby spits up and it pools over the opening to trachea. It is actually easier to aspirate when you're on your stomach, because of gravity.

Some parents like statistics, others don't. Since Back to Sleep, there is no increased incidence in aspiration. So if sleeping supine were a problem, we would see more of a problem with aspiration.

The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition wrote a policy statement. (Vandenplas, Rudolph et al., 2009) Infants with GE reflux should be supine except for the rare infant where risk for death from complications of GE reflux is greater than the risk of SIDS — (e.g. kids with neuromuscular disorder, sedated, airway anomalies — really rare things like type 3 laryngeal cleft). Even though putting babies in the prone position helps reflux, they say don't do it.

When the baby is on her back, elevating the head of the crib doesn't do anything for reflux. (Meyers and Herbst 1982; Tobin, McCloud et al., 1997) The baby may slide to the bottom of the crib and end in a compromised position all scrunched up; this makes it harder to breathe.

Car seats and sitting devices

If you put babies in car seats, it actually makes reflux worse (Orenstein, Whitington et al., 1983) because they are scrunched up and it also makes respiration hard. There is a study from Canada that babies who sleep in sitting devices, particularly preemies, don't oxygenate well. (Cote, Bairam et al., 2008) There are reports of babies who have suffocated in a car seat on the floor where a sibling has climbed into it.

So, there is no evidence that these "legends" help the reflux.

If the baby is in pain and not gaining weight, send them back to pediatrician to medically treat the reflux.

What do we do when parent says "My doctor says" and the doctor is wrong?

- Hint we cannot contradict the doctor, but we can say to the family "here is the AAP policy, take it to them and talk to your doctor about it."
- Call the doctor and start the discussion in terms of the family's perceptions about what he/she said. Indicate that this may not be what the doctor intended the message to be.
- If the doctor is actually advocating something contrary to current evidence, ask the other doctor to send articles with evidence for their position. Saying something like "I haven't seen those studies; could you share them with me?" People go on tradition and what makes sense, and don't go by the literature.

Try to make it as concrete as possible for families. If they don't understand, they will just see you as one more person giving a different opinion and may ignore them all.

The Message: Back positioning on a safe, flat surface for all babies with reflux, unless the risk of death from reflux is greater than the risk of SIDS.

Use a car seat for transportation in the car, not as a routine sleep place for the baby.

Scenario 2. You are seeing the parents of a 2 week old boy who was born at full term with no complications. The mother tells you that the baby sleeps in the bed with her and her husband, because it makes it easier to feed him in the middle of the night. She breastfeeds, but also supplements with formula. Neither she nor the father is a smoker.

How would you handle the scenario?

We would need to do some understanding before the preaching. See what they know about sleep position, sleep surface, feeding, and the difference between co-sleeping and bed sharing. We would talk about things they were doing well like not smoking and breastfeeding. We would also talk about bed sharing vs co sleeping and how to implement that. One approach is to bring out the recommendations of the AAP and CDC — we are comfortable that these are easy to discuss. It is important to engage the dad at the appointment.

Group Discussion

In Alaska, they are struggling with categorically always saying 'no bed sharing'. There is some evidence in their state that bed sharing is not an independent risk factor if parents are not smoking or impaired, and the baby is on his/her back. There are some studies that say a lot of families bed share, and most don't die. A 12 year review of deaths didn't show bed sharing as an independent risk factor.

There are lots of cultural issues that go along with the bed sharing issue.

One county review of deaths in 9 years reported that when parents' weight was on the death certificate, it was a significant factor — 60% of the babies who died were in bed with over 500 pounds of adult weight.

If people are adamant, do we give a list of how to do this safely? This is recommended by McKenna and others. However, if parents realize they are not doing it safely — will that lead to them not doing it?

The discussion is made more difficult because people use different terms to mean the same thing, or the same term to mean different things. Co-sleeping is defined as being in close proximity (on the same or different surfaces), close enough to be able to see, hear and touch each other. This includes bed sharing or room sharing without bed sharing. Bed sharing is a specific type of co-sleeping when the infant is sleeping on the same surface with another person. These definitions are from McKenna. (McKenna 2007)

There are reports of infant deaths on a Snuggle Nest. One report of infant death on memory foam — Nap Nanny.

Current Research Related to Scenario 2

Why do families bed share? Convenience (for feeding and monitoring baby) is important. Studies indicate that in the African American community bed sharing is seen as a way for the parent to maintain vigilance to keep baby safe — so if they put the baby on his/her stomach they know it is risky and thus are more likely to bed share. Mothers also reported keeping baby in bed to protect them from threats such as rats, bugs, random kidnappings, and gun fire. (Joyner, Oden et al., 2010)

Some studies indicate that not only is bed sharing convenient for feeding, but initiation and maintenance may be greater with bed sharing.

Some bed sharing advocates note that there is bed sharing in cultures with low SIDS rates — but sleep surfaces are firm mats on the floor, a separate mat for the infant, no soft bedding.

There are no subgroups of the population for whom bed sharing has been found in epidemiologic studies to be protective against SIDS and SUID. While some observational studies say bed sharing is ok, they have small numbers of subjects. To do studies on SIDS we have to have thousands. Some studies may find that something is protective in only univariate analysis. For instance, early studies looking at breastfeeding and SIDS found that breastfeeding was protective, but only in univariate analysis. When they controlled for confounding factors, the relationship was not demonstrated, because breastfeeding moms in those studies also tended to get prenatal care, didn't smoke, etc. It was difficult to say whether it was breastfeeding or the other factors that provided the protection against SIDS. (More about breastfeeding and more recent studies later.)

Evidence on when it is safe to bed share

Demonstrating safety is harder than demonstrating risk. It is difficult to collect sufficient numbers in subgroups, e.g. breastfeeding mothers who do not smoke, have not consumed alcohol, don't take drugs — hard to find enough of those to test. In addition, there is a lot of stuff in bed sharing that you cannot control, such as weight, parent fatigue, overheating.

We do have evidence on what makes bed sharing especially dangerous.

- One or both parents are smokers (OR 2.3-17.7)
- Excessively soft surfaces, such as waterbeds, sofas, and armchairs (OR 5.1-66.9)
- Soft bedding accessories such as pillows or blankets are used (OR 2.8- 4.1)
- Multiple bed sharers (OR 5.4)
- o Parent has consumed alcohol (OR 1.66)
- o Infant is < 2-3 months of age (OR 4.7-10.4), even if parents don't smoke
- o Bed sharing with someone who is not a parent (OR 5.4)
- Bed sharing for longer duration

All of the bed sharing studies have only looked at SIDS. Now we are seeing other types of death. None of the studies look at suffocations and undetermined.

Evidence of the impact of bed sharing on breastfeeding

The two are so tightly linked, it's hard to know which is the chicken and which is the egg; Is bed sharing making breastfeeding better or is it that people who know they will breastfeed decide to bed share?

Make your recommendations positive — put the crib next to your bed — the baby is right there and you don't have to worry about pillows, etc. So you can sleep better and baby has his own space.

The Message: Tell them that most babies are dying in beds. Ask father about bed sharing—fathers not so positive and also think about what will happen when the child is 2 years old. Room share, not bed share

Breastfeed

Encourage dad to help with supplemental feedings

Note: Professional responsibility and liability — parents say no one ever told me, people are reluctant to tell, should share the info. Also, there is a concern about CDR prosecuting families who have the knowledge and didn't follow through. There is a civil case where a baby sitter is being sued for putting the baby on the stomach and soft surface.

Scenario 3. You are talking with a mother who recently had twins. The twins were born at 34 weeks; one weighed 4 pounds and the other 5 pounds at birth. They were in the transitional nursery for 10 days until the smaller one gained enough weight to go home. They are now 1 month old. She tells you that they are sleeping in a single crib in the same room as her and her husband, because it helps them when they are together. They slept in the same bassinet in the nursery.

How would you handle the scenario?

It is very important to ask why they're doing what they're doing. Go back to beginning — what did the nurse do? (There is a need to educate nurses and doctors on the AAP guidelines.) The Guidelines don't directly address twins, but do state that babies should not share a sleep surface with a sibling. NANN (National Association of Neonatal Nurses) policy does not support co-bedding multiples. Praise them for room sharing. Investigate to see if they cannot afford two cribs — if so you could help out. Educate also grandparents, baby sitters, etc.

Group Discussion

Question — is there a way when twins are small to make one crib into two safe sleeping surfaces. Devices? There is no research.

Is there any evidence that if you don't have two cribs, you can put their heads at alternate ends of the crib? No evidence.

Current Research Related to Scenario 3

When giving these messages — there are studies to show it is dangerous and no study to say that there is a benefit, so why not keep baby safe.

Reasons for co-bedding multiples — psychological and physiologic positive effects in anecdotal and observational studies. There are 8 analytical studies that have looked at co-bedding and positive effects (summarized in Tomashek and Wallman 2007).

- Length of stay one found babies had fewer blood infections when they compared data from day 7, but co-bedding began at day 13
- Weight 2 found statistically different, but not clinically different weight gain if co-bedded
- Physiologic stress one study found a difference in high activity heart rate, but no other changes in stress cues, baseline heart rate, respiratory rate, oxygen saturation
- Apnea one study found fewer apneas <10 sec, but no difference in apneas <15 sec. No differences in bradycardia
- Parental attitudes mixed satisfaction

Disadvantages of co-bedding multiples

- Twins and higher order multiples are often premature and with low birth weights; at increased risk for SIDS. Increased potential for overheating and re-breathing
- Increased risk of accidental suffocation
- Most co-bedded twins placed on side
- Co-bedding of twins in the hospital setting may encourage parents to continue this practice at home

The Message: Separate cribs for twins in parents' room. Portable cribs or playpens may work better because of space.

Scenario 4. You are talking with a woman who is 34 weeks pregnant with her first child. She thinks that she wants to try to breastfeeding, but isn't sure. Her brother died of SIDS and she has read conflicting information about whether breastfeeding can prevent SIDS or not. She wants to know what you think.

How would you handle the scenario?

First, the whole group was for breastfeeding. We need to find out where she got her information and then have the proper resources there for her. It depends how old she is and how old she was when her brother died — there is new information, etc. How old was the mother? How did she translate what she was told? Or did she just read it and tried to make sense of it? We were comfortable telling her to institute breastfeeding and give new safe sleep information.

We would ask where she is getting prenatal care, where would she deliver. How much info did she receive on breastfeeding? Any information on her access to a lactation nurse? Did she use WIC? Identify her primary care person and who, if anyone, gave her info on breastfeeding? Could she enroll in Healthy Start? Her question is complicated by brother's death.

Group Discussion

I would suggest she has support in the first few days of breastfeeding. Incorporate the father in the education.

Current Research Related to Scenario 4

Why parents may not want to breastfeed:

• It's inconvenient

- They are embarrassed
- Concern about pain
- Resistance of other parent, other family members, friends
- Conflicting feelings about breasts
- Returning to work and difficult to do at work so why start
- Mother may have health problems
- Women who smoke
- Some women are afraid to fail
- Some nurses do not promote it in the hospital

Earlier epidemiologic studies were not consistent in demonstrating a protective effect of breastfeeding with regards to SIDS risk per se. Breastfeeding was found to be protective in univariate analysis, but in not multivariate. Factors associated with breastfeeding are the protective factors. (See above.)

AHRQ (Agency for Healthcare Research and Quality) did a meta-analysis on multiple outcomes of breastfeeding including SIDS. Six studies were analyzed. That analysis indicates that ever breast feeding yielded a summary OR .41 adjusted 0.64 for SIDS or the risk decreased by 60%. (Ip, Chung et al., 2009) In a German study, now the largest study, they found that exclusive breast feeding at 1 month of age halved the risk, but partial breastfeeding did not reduce risk. (Vennemann, Bajanowski et al., 2009) Hauck et al conducted a meta-analysis of 23 studies (not yet published). Any breastfeeding halved the risk of SIDS, and if the baby was breastfed longer or exclusively breastfed, it was even more protective.

There is also evidence, however, that the benefits of breastfeeding do not outweigh the risk of bed sharing. (Ruys, de Jonge et al., 2007) A study in New Jersey by Ostfeld looked at all bed sharing deaths and 1/4 were breastfed. (Ostfeld, Perl et al., 2006)

The Message: Breastfeeding, exclusively if possible; the more exclusive and the longer the better. Baby in own sleep area next to parents' bed.

Primary care provider needs to know about family history.

Make sure she has support in the first few days of breastfeeding.

Tell her that the most recent studies do show breastfeeding as a protective factor, and provide her with the information.

Note: What is the genetic risk for her child? We don't know. If you had one child die of SIDS, the next child may be at slightly higher risk for SIDS, but it's difficult to say definitively, because all of the studies of siblings have very small numbers.

Do recommend going to a genetics counselor, newborn screening for fatty acid disorders. Get the newest info to the health practitioner and address negative attitudes of labor and delivery nurses who may treat breast milk as dirty, etc.

Scenario 5. Several of the nurses at your hospital recently attended a workshop on "The Happiest Baby on the Block" which strongly advocates swaddling. They would like to make swaddling an integral part of nursery protocol. The Nursery director is ambivalent and asking for input.

How would you handle the scenario?

We would say that there seems to be no evidence on the benefits of swaddling. Maybe it's being done to help calm a fussy baby, but because there are no studies, we don't know if there are problems with

swaddling done incorrectly or for too long. Does it impact motor development? Don't know how to do correctly and no evidence for what that is.

Current Research Related to Scenario 5

Reasons for swaddling:

- So baby will stop crying
- To keep baby warm
- · Keep baby from startling
- Promotes sleep
- Fall asleep faster, longer fewer spontaneous awakenings
- Tradition
- Seeing in hospital
- Friends are doing it

There is good anecdotal evidence that swaddling helps quiet babies—products, books. We might hope that swaddling does show that if done correctly, it can calm baby and keep baby on the back and stop the impulse to bring the baby into bed. We need studies and evidence that it is good in some way and then develop recommendations so it is not harmful. There is evidence that swaddling increases cortical arousal thresholds in some babies — it takes longer to wake up some babies and especially if not routinely swaddled. (Richardson, Walker et al., 2009; Richardson, Walker et al., 2010)

If they are swaddled too tightly, it decreases functional lung capacity. If the hips are wrapped too tightly and straight down, swaddling can increase the risk of hip dysplasia. There's overheating if the baby has a fever or the head is covered. One study found that there is no overheating in a light cotton blanket from the shoulders down (Richardson, Walker et al., 2009) There are conflicting findings about SIDS when swaddled. There are findings of a decrease in SIDS rates with swaddling if on the back, but increase if swaddled on stomach. Peter Blair found a 31-fold increase in SIDS risk with swaddling, but did not stratify by sleep position and it was a small sample.

Preliminary data from one study in Washington DC demonstrate that babies who would have been put on stomach for sleep were more likely to be put on their backs to sleep if swaddled. A study in Netherlands — babies do better when swaddled, but parents who swaddled had more routines and that was soothing. Swaddling is most protective if swaddling is the culture of family — if learned from people who truly knew how to swaddle.

Issues in the NICU may be different.

There are now many products for swaddling that seem to have inherent dangers — padding around the head, ways to tie around the baby, etc.

Few discussions deal with the length of time — is it for 1 week or months?

The Message: Give the question back to the nurses to find the evidence base to show there is a benefit. If we don't know that there is a benefit and know there is some potential risk — e.g., loose blanket, can cover nose and mouth. If there are concerns, then better to not do it. We cannot ignore Happiest Baby on the Block — have to talk about the fact that there is no evidence and it's only

talking about this for 3 months. Teach that at 8 weeks crying will peak and that is normal, so parents will not think they are a bad parent or that something is wrong with their baby.

Scenario 6. You are conducting a home visit with a family with a 2 week old infant. The infant was in the hospital for 5 days because of maternal fever. The family has both a pack-n-play and a crib in the home. The baby wasn't sleeping well in the pack-n-play, so the grandmother put a pillow between the mattress and the sheet to "soften it up." The sheet is taut over the pillow. The family has also prepared the crib and has put bumper pads for when the baby sleeps there.

How would you handle the scenario?

Find out why they are using the pack-n-play

Find out if there is any night time routine

Ask about the baby's sleep — the grandmother may think the baby is not sleeping well or not comfortable so identify why the baby is not comfortable and normalize infant sleep behavior Do some education, visuals, demonstrate with a doll placed against the bumper pad Talk to all care givers and talk to mom alone — there might be some pressure from grandmother — and find out how she feels. If she wants to change things, she might be able to blame it on the home visitor. Some parents will appreciate the AAP guidelines —"lots of doctors from all over studied the research and came up with these recommendations"

Group Discussion

To care givers, softness equates comfort. Brainstorm ways to increase comfort — massage before bed, room sharing.

Explain to parents that babies are born to cry, eat and sleep and their comfort is not similar to ours. They can get used to sleeping on back and firm mattress.

Why parents use soft bedding:

- Comfort the baby sleeps better or the parent perceives soft as more comfortable
- Safety soft surfaces cushion bumps (pads)
- Temperature baby will get cold on the hard surface
- Tradition and aesthetics everybody does it, theme for the nursery, if they sell it, it's safe
- Firm means comfortable, flat, not lumpy, not too soft, not too hard. Some parents think that firm means taut, so they pad the mattress, then cover tautly with sheet
- JLo [Jennifer Lopez] does it

Reasons for bumper pads:

- Safety hits head, leg gets caught, if baby scoots in corner, worried about social services if get bruises
- Aesthetics
- Wouldn't sell if not safe

Current Research Related to Scenario 6

CPSC pillow data — 531 deaths associated with pillows or cushions:

- most found prone
- half on top of pillow
- others smothered in crowded sleep surfaces

- most less than 4 months
- one-quarter in cribs, others in beds or sofas

Thach reported that CPSC deaths due to bumper pads were from 3 mechanisms: (Thach, Rutherford et al., 2007)

- suffocation against soft bumper pads
- entrapment between firm pads and mattress
- strangulation from the ties

And in young infants bumper pads don't prevent injury — they cannot move with enough force to get hurt. Limb entrapment for young infants does not result in injury.

Bumper pads obscure visibility and increase parent anxiety so they then take the baby into their bed.

The Message: Take out the bumper pads (what about mesh ones and things that wrap around each crib rain with Velcro? Too new, if they don't help why use them?)

All reported injuries in cribs without bumpers are in toddlers

No pillows

No blankets, stuffed animals, no sheepskin

Talk with grandma

Any surface meant for an adult is too soft

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