

EXAMINING ATTITUDES TOWARD INFANT SAFE SLEEP RECOMMENDATIONS  
AMONG AFRICAN AMERICAN MOTHERS AND GRANDMOTHERS

by

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(Under the Direction of Jessica Muilenburg)

ABSTRACT

African American infants are twice as likely to die from sleep-related infant deaths than are infants of other races. Despite the perceived simplicity of infant safe sleep recommendations, data indicates that African American mothers are less likely to follow infant safe sleep recommendations. Grandmothers play an important role in influencing a mother's decision to follow infant safe sleep practices. Thus, there is a critical need to identify factors that impact African American mothers and grandmothers' decisions to follow established safe sleep practices and incorporate such aspects in infant safe sleep interventions. This dissertation examines attitudes about infant safe sleep interventions among African American mothers and grandmothers who are likely to perform caregiver responsibilities and influence caretaking decisions such as infant sleep to develop recommendations for a culturally tailored infant safe sleep intervention to increase adherence to evidence-based infant safe sleep recommendations.

INDEX WORDS: Sudden Infant Death Syndrome, SIDS, infant sleep-related death, African American mothers, African American grandmothers

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## CHAPTER 1

### INTRODUCTION

Sudden unexpected infant death (SUID) has been studied extensively in the United States since the 1960s (Ottaviani, 2011). SUID is defined as the death of an infant less than 1 year of age that occurs suddenly and unexpectedly, and whose cause of death is not immediately obvious prior to investigation. SUID encompasses sudden infant death syndrome (SIDS), unknown cause and accidental suffocation or strangulation (Barnes-Josiah et al., 2007). The term, “SIDS” was first proposed in 1969 to refer to a distinctive subgroup of unexpected infant deaths occurring during the post neonatal period with relatively consistent clinical, epidemiological, and pathological features (Beckwith, 2003). In 1974, Congress passed the Sudden Infant Death Syndrome Act of 1974. Following this act, SIDS became recognized as a significant public health issue and Congress directed the National Institute of Child Health and Human Development (NICHD) to take the lead on SIDS research within the U.S. Public Health Service (Tooley, 1975).

In the 1980s, the United States, along with New Zealand, Australia and Europe reported alarmingly high rates of SIDS (National Institute of Child Health and Human Development [NICHD]). By contrast, during the same period, Hong Kong, where the common practice was to place infants to sleep in a supine position (on their back), reported extremely low rates of SIDS deaths (also known as cot death) (Davies, 1985). Between 1980 and 1984, Hong Kong had only 15 documented cases of cot death, an approximate incidence of 0.036 per 1000 live births (Davies, 1985).

In 1989, the NICHD developed the current definition of SIDS as the sudden death of an infant under 1 year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history (Moon et al., 2017). Although SIDS remains a major public health concern, great progress has been made in reducing SIDS deaths in the past three decades. Between 1983 and 1994, 61,882 infant deaths were attributed to SIDS (Ahlers-Schmidt et al., 2017). According to the Centers for Disease Control and Prevention (CDC), SIDS rates fell from 130.3 deaths per 100,000 live births in 1990 to 39.4 deaths per 100,000 live births in 2015 (CDC, 2017).

In 1992, the American Academy of Pediatrics (AAP) first recommended that infants sleep on their backs or sides (In 2000, AAP recognized back sleeping as the exclusive recommendation) to reduce the risk of SIDS. Following the recommendation, the National Institute of Child Health and Human Development (NICHD) launched the *Back to Sleep* campaign (now known as the *Safe to Sleep* campaign). The campaign emphasized placing infants on their back to sleep (Ahlers-Schmidt, Schunn, Dempsey, & Blackmon, 2014; Moon, 2011). Between 1994 and 2001, SIDS deaths declined by more than 50% (Von Kohorn et al., 2010). Despite this success, since 2001, adherence to supine sleep recommendations has plateaued (Hauck, Tanabe, McMurry, & Moon, 2015). In 2015, 3,700 infants died from an infant sleep related death (CDC, 2017). Of these deaths, SIDS was responsible for 43% (1,600), thereby making SIDS the leading sleep-related cause of death of infants less than one-year-old (Barnes-Josiah et al., 2007).

### **Infant Sleep-Related Death Disparities**

Infant mortality is a key indicator for overall population health, as infant mortality is associated with several factors that influence overall health outcomes, including maternal health,

socioeconomic conditions and public health practices (He, Akil, Aker, Hwang, & Ahmad, 2015; Stampfel et al., 2012). Infant mortality is measured by the infant mortality rate (IMR), which is the number of deaths of children under one year of age per 1000 live births (CDC, 2018). Although significant progress has been made in reducing infant mortality over the last 50 years, the United States still has one of the highest IMRs among developed countries, with 5.9 deaths per 1,000 live births in 2015 (Chen, Oster, & Williams, 2016). Significant racial and ethnic disparities exist in infant mortality rates in the United States (Braveman, Egerter, & Mockenhaupt, 2011). In 2015, Whites had an overall IMR of 4.9 infant deaths per 1,000 live births compared to the IMR of Blacks, which was 11.3 per 1,000 deaths. Infants born to families experiencing higher rates of poverty typically have higher infant mortality rates compared to infants born to families with higher socioeconomic backgrounds (Braveman, Cubbin, Egerter, Williams, & Pamuk, 2010; Chetty et al., 2016; Cooper et al., 2016; Komro, Livingston, Markowitz, & Wagenaar, 2016).

As previously mentioned, SIDS is a major contributor to infant mortality and similar racial and ethnic disparities persist in rates of infant sleep related deaths (Hauck, Tanabe, & Moon, 2011). African American infants are two to three times more likely to die from SIDS than White infants (E. R. Colson et al., 2009; Fern R Hauck et al., 2003; Keene Woods, Ahlers-Schmidt, Wipperman, & Williams, 2015; A. Mathews et al., 2016; Smith et al., 2010). In 2015, rates (per 100,000 live births) of sleep related infant deaths were highest among American Indians/Alaskan Natives (194.1), followed by non-Hispanic Blacks (170.2) (CDC, 2017).

Studies have found that although SIDS deaths dramatically declined following the *Back to Sleep* campaign, the campaign was less effective in reducing social inequalities. In fact, infant

sleep related death disparities widened after the campaign (Gollenberg & Fendley, 2018; Pickett, Luo, & Lauderdale, 2005).

### **Infant Sleep-Related Deaths in Georgia**

In addition to racial and ethnic disparities, substantial regional differences in infant sleep related deaths exist (Bombard et al., 2018). Data from a recent study indicate that Southeastern states (Alabama, Florida, Georgia, Mississippi, and Louisiana) account for most of these deaths (He et al., 2015). Sleep-related infant deaths are the third leading cause of infant mortality in Georgia (GCFRP, 2016). In 2016, 152 infants died due to sleep related causes in Georgia, with most of these deaths taking place in metropolitan Atlanta (Counties: DeKalb, 13; Fulton; 11, Cobb, 9; Gwinnett, 8; Clayton,4) (Georgia Child Fatality Review Panel [GCFRP], 2016). Of these deaths, 61% were African American, 58% were male and 66% occurred among infants less than four months old, with the majority (92%) of deaths occurring before infants reached 6 months old (GCFRP, 2016). These findings are consistent with national trends. Nearly 90% of SIDS deaths occur before an infant turns 6 months old with deaths peaking between 2 and 4 months (Hunt & Hauck, 2006; Shapiro-Mendoza, Tomashek, Anderson, & Wingo, 2006; Stephens, Bancroft, Glaros, & Lowe, 2010; Trachtenberg, Haas, Kinney, Stanley, & Krous, 2012b). As discussed above, while SIDS affects all infants of all racial and ethnic populations, African American infants are particularly vulnerable. Nationwide, African American infants are two to three times more likely to die from an infant sleep related death than white infants (Anachebe, 2006; Anachebe & Sutton, 2003; T. Mathews, MacDorman, & Thoma, 2015). Males are more susceptible to SIDS. Studies have demonstrated that infant boys are 30 to 50% more likely than infant girls to die from an infant sleep related death (Hunt & Hauck, 2006; Trachtenberg et al., 2012b).

Death scene investigations conducted by GCFRP (2016) revealed that 56% of these deaths occurred in an adult bed, whereas 17% of these deaths occurred in a crib or bassinette. Approximately 50% of SIDS occurrences transpire when infants are sharing a bed, sofa, or sofa chair with another person (Fern R. Hauck, Thompson, Tanabe, Moon, & Vennemann, 2011; Keene Woods, Ahlers-Schmidt, Wipperman, & Williams, 2015; Kinney & Thach, 2009) such as, a sofa or arm chair with infants, has been found to increase the risk of SIDS (Carpenter et al., 2013; Louise Flick, White, Vemulapalli, Stulac, & Kemp, 2001; F. R. Hauck, S. M. Herman, M. Donovan, S. Iyasu, C. M. Moore, et al., 2003; Moon, Darnall, Feldman-Winter, Goodstein, & Hauck, 2016; Tappin, Ecob, & Brooke, 2005) A number of research studies have found that African American mothers are more likely to bed share (Laura M Gaydos et al., 2015; Brandi L Joyner, Rosalind P Oden, Taiwo I Ajao, & Rachel Y Moon, 2010; Liebrechts-Akkerman et al., 2011; Moon & Omron, 2002; Tong, England, & Glantz, 2005).

In 20 of the bed sharing cases in Georgia, the infant was sleeping with an adult and at least one other child (GCFRP, 2016). In 4 cases, investigations revealed that another child (usually a sibling) was sleeping with the infant at the time of death. Research findings from previous studies indicate that the risk of SIDS increases when multiple bed sharers are present (Fu, Colson, Corwin, & Moon, 2008; F. R. Hauck, S. M. Herman, M. Donovan, S. Iyasu, C. Merrick Moore, et al., 2003; Syndrome, 2005). A striking revelation is that 41% of the bed sharing infants in Georgia were found in the supine position, compared to 11% of infants sleeping found sleeping alone. This finding suggests that the protective factor that the supine position provides against SIDS is less effective when other risk factors are present (GCFRP, 2016).

Secondary caregivers, such as grandparents, relatives, child care providers are more likely to place infants prone, increasing the risk of SIDS (Carlin & Moon, 2017; Moon, Horne, & Hauck, 2007). However, investigation findings in Georgia do not support this claim. In fact, 80% of the identified supervisors at the time of death were also the infant's primary caregiver (parent) (GCFRP, 2016). Several organizations including AAP, NICHD and GDPH recommend providing infant safe sleep education to all caregivers (Centers for Disease Control and Prevention[CDC], 2017; Moon et al., 2016).

For one, new mothers often rely on the advice they receive from their social networks, particularly their own mothers and senior female relatives, to inform and shape their parenting choices. Caraballo et al. (2016) argues that although grandmothers usually offer parenting advice in an effort to help their children become good parents, grandmothers may be sharing antiquated information. In one study which set out to determine how African American mothers of infants between 0 to 6 months of age perceive interactions with healthcare professionals and overall care of infants, Coleman (2009) found that African American mothers are more likely to follow advice about infant sleep positions and sleep environments from a grandmother, close female relative or friend rather than their nurse's recommendations.

Furthermore, when grandmothers live in the home or perform caregiver responsibilities, infants are more likely to be placed in the prone sleep position (Aitken et al., 2016; Brenner, Simons-Morton, Bhaskar, & et al., 1998; Flick, Vemulapalli, Stulac, & Kemp, 2001; Mathews et al., 2016a; Moon, Oden, & Grady, 2004; Moon & Omron, 2002). In a study surveying grandmothers to assess their views and behaviors regarding to infant safe sleep, Aitken et al. (2016) found that fewer than half of the respondents reported placing the infant in the supine sleep position and in a safe sleep environment when they were caring for the infant in their own

home, and only 58% reported following the infant safe sleep recommendations when caring for the infant in the home of the infant's mother. Similarly, in a recent study Chesser, Ahlers-Schmidt, and Schunn (2019) found that grandparents may not be the most knowledgeable about the safest sleep choices for infants. Overall, these studies highlight the need for interventions that focus on providing safe sleep education to senior caregivers.

Maternal smoking has been identified as a significant risk factor for SIDS. In the past decade, SIDS research has provided ample support for the assertion that, infants born to mothers who smoked during pregnancy have an increased risk of SIDS compared with infants born to women who had not smoked during pregnancy (Ball & Volpe, 2013; Liebrechts-Akkerman et al., 2011; Wisborg, Kesmodel, Henriksen, Olsen, & Secher, 2000). The literature has also documented that infants born to mothers who smoked during pregnancy are three times more likely to die of SIDS than those born to mothers who did not smoke during pregnancy (Tong et al., 2005). Along similar lines, infants who are exposed to secondhand smoke in the home are two times more likely to die from SIDS (Tong et al., 2005). Correspondingly, 33% of Georgia mothers of a decedent reported smoking before and/or during the pregnancy. In 31 deaths, the caregiver had a reported history of drug abuse; of those, 22 were bed sharing at the time of death (GCFRP, 2016).

In the past decade, the number of pregnant women who use opioids (licit and illicit) have skyrocketed (Patrick & Schiff, 2017). Between 1998 and 2011, the prevalence of opioid use disorder during pregnancy doubled to 4 per 1,000 deliveries (Maeda, Bateman, Clancy, Creanga, & Leffert, 2014). Previous studies have documented that illicit substance use during pregnancy is associated with an increase in SIDS (Chavez, Ostrea Jr, Stryker, & Smialek, 1979; Kandall & Gaines, 1991; Rajegowda, Kandall, & Falciglia, 1978). The extent to which prescription opioid



use during pregnancy may be attributed to SIDS remains unclear. However, a few studies have found that chronic untreated opioid addiction during pregnancy is associated with a number of risks for both the mother and the infant, including poor fetal growth, birth defects and preterm birth, which have previously been identified as risk factors for infant sleep related deaths (American College of Obstetricians and Gynecologists, 2017; Goodman, Milliken, Theiler, Nordstrom, & Akerman, 2015).

African American infants are twice as likely to die from SIDS as infants from other races (Mathews et al., 2016). Certain sleeping practices that increase the risk for SIDS, such as placing the infant in the prone sleeping position, using soft bedding, and bed sharing are more common in African-American households (Mathews et al., 2016). Furthermore, grandmothers play an important role when it comes to influencing a mother's decision to follow infant safe sleep practices. Multiple studies have found that when a grandmother is in the home or regularly cares for their infant grandchildren, infants are more likely to be placed in the prone sleeping position (Aitken et al., 2016; Eve R Colson et al., 2005; Gaydos et al., 2015).

*In this dissertation, the term "SIDS" and "infant sleep-related death" will be used interchangeably to refer to all infant sleep related deaths caused by SUID, SIDS, suffocation, strangulation and asphyxiation.*

## **Purpose of the Research**

The purpose of this qualitative research study was to explore perceptions about infant safe sleep interventions among African American mothers and grandmothers who are likely to perform caregiver responsibilities and influence caretaking decisions such as infant sleep to develop recommendations for a culturally tailored infant safe sleep intervention to increase adherence to evidence-based infant safe sleep recommendations.

**Research aims.** This study was guided by the following specific aims:

1. Describe African American mothers and grandmothers' beliefs and perceptions of infant's risk susceptibility for an infant sleep-related death.
2. Describe African American mothers and grandmothers' attitudes toward established infant safe sleep recommendations.
3. Describe African American mothers and grandmothers' perception of baby boxes for use of an infant sleep environment.

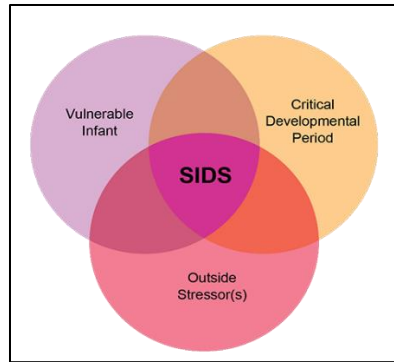
## CHAPTER 2

### LITERATURE REVIEW

This literature review will discuss risk and protective factors for SIDS, infant safe sleep disparities including, infant sleep positions and sleep locations, as well as the health literacy of infant caregivers. There is a critical need to identify the factors that interfere with African American mothers and grandmothers' decisions to follow infant safe sleep practices. Most sleep-related infant deaths are largely preventable. Thus, investigating the reasons African American mothers fail to comply with infant safe sleep recommendations is an important public health priority. The contributions of this researchers will be valuable to health promotion practitioners in developing effective and culturally relevant interventions that focus on following safe sleep practices.

#### **Causes of SIDS**

Although SIDS has been widely studied, the exact cause of SIDS is still not fully understood. Several hypotheses have been proposed to explain the causes SIDS. One of the most popular hypotheses is the Triple Risk Model (TRM). The TRM suggests that SIDS occurs when the following combination of factors are present: (1) vulnerable infant, (2) critical developmental period, and (3) external stressors (Filiano & Kinney, 1994; Guntheroth & Spiers, 2002; Trachtenberg et al., 2012b).



**Figure 1. Triple Risk Model**

According to researchers, the term “vulnerable infant” refers to newborns that are predisposed to SIDS due to certain genetic and physiological conditions (Elwell & McDonagh, 2011; Filiano & Kinney, 1994). The TRM states that the critical developmental period occurs during 12 months of life, however it is important to note that the primary focus is on the first one to four months of life, because SIDS peaks between the ages of 1 and 4 months (de Luca & Hinde, 2016; Haglund & Cnattingius, 1990). Outside stressors include environmental stressors, such as a stomach sleep position, overheating, secondhand tobacco smoke, or an upper respiratory tract infection (Trachtenberg et al., 2012b). Most infants can survive an encounter with an outside stressor; however, an already vulnerable infant may not be able to overcome them. Although these stressors are not believed to independently cause infant death, they may offset a vulnerable infant's chances of survival.

### **Intrinsic and Extrinsic Risk Factors**

In addition to the risk factors outlined in the TRM, researchers have also identified specific intrinsic and extrinsic risk factors (Trachtenberg et al., 2012b). Intrinsic risk factors refer to genetic or environmental factors that affect susceptibility, these include African American race, male gender, prematurity (37 gestational weeks at birth), and prenatal maternal smoking or alcohol intake (Trachtenberg et al., 2012b). Extrinsic risk factors are defined as physical

stressor(s) around the time of death that may increase the risk of SIDS for an already vulnerable infant (Trachtenberg, Haas, Kinney, Stanley, & Krous, 2012a). These factors include being placed or found in a prone/side sleep position, found face-down, head covered, sleeping on an adult mattress, couch, or playpen, soft bedding, bed-sharing, and signs of upper respiratory tract infection (Trachtenberg et al., 2012b).

### **Infant Safe Sleep Disparities**

As previously mentioned, sleep related infant deaths disproportionately affect minorities, particularly African-Americans. African American infants are twice as likely to die from SIDS as infants from other races (Colson et al., 2009; Fern R Hauck et al., 2003; Keene Woods et al., 2015; A. Mathews et al., 2016a; Smith et al., 2010). Previous research found that certain sleeping practices that increase the risk for SIDS, such as placing the infant in the prone sleeping position, using soft bedding, and bed sharing are more common in African-American households (Flick et al., 2001; Hauck et al., 2003; Hauck, Tanabe, & Moon, 2011; Mathews et al., 2016a; Scheers, Rutherford, & Kemp, 2003).

A compelling body of evidence indicates that African American mothers are knowledgeable of; however, do not accept safe sleep recommendations (Ajao, Oden, Joyner, & Moon, 2011; Gaydos et al., 2015; Herman, Adkins, & Moon, 2015; Joyner et al., 2010).

Although SIDS is more likely to occur to families of lower socioeconomic status, infants born to college educated African American women have similar SIDS rates as infants born to Hispanic or Asian or Pacific Islander women who did not complete high school (Hauck et al., 2011).

Overwhelming evidence suggests that mothers make decisions about their infants' sleep locations and positions based on their perceptions of their infants' physical and emotional comfort and perceptions of what was safe, effective, and convenient in meeting the needs of their

infants while also meeting their own need for rest (Ajao et al., 2011; Canter, Rao, Patrick, Alpan, & Altman, 2015; Colson et al., 2005; Joyner et al., 2010). Previous research also found that mothers expressed that the opinions of health professionals and educational materials did not address the differences among infants in terms of sleep behavior and environmental comfort (Herman et al., 2015).

Some researchers suggest that misconceptions about SIDS continue to persist and ultimately may be responsible for some mothers' inaccurate beliefs about the dangers of certain sleep practices. In their qualitative study of African American mothers, Colson et al. found that several participants possessed a lack of knowledge about SIDS and SIDS risk factors (Colson et al., 2005). Some mothers believed that SIDS, which is also referred to as "crib death" could only occur if the baby was sleeping in a crib. Another study revealed that some mothers believe SIDS is a disease or syndrome and therefore, one can't protect their infant from SIDS (Herman et al., 2015) These results demonstrate that there is still a need to dispel myths about SIDS and educate parents about infant safe sleep practices (Chung-Park, 2012). In addition, many parents do not believe that their behavior except for vigilance can affect SIDS risk because they view SIDS as a random act of God (Hauck et al., 2011).

### **Supine Sleep Position**

Multiple studies have indicated that infant prone sleeping is associated with an increase of SIDS (Smith et al., 2010; Trachtenberg et al., 2012b). Even more prone sleeping has been found to be the most significant extrinsic risk factor for SIDS. Several studies have found that many parents choose to place their infant(s) in the prone position due to concerns that their baby will choke on vomit if placed on his back for sleeping (Colson et al., 2009; Maindonald, 2005). Infant comfort has also attributed to the decision to place the infant in the supine sleep position.

To reduce the risk of SIDS, AAP recommends that infants should be placed for sleep in a supine position for every sleep by every caregiver until the child reaches 1 year of age (Moon et al., 2016).

As previously mentioned, since 2000 the AAP has recognized that side sleeping is not safe and is not advised (Moon et al., 2016). The AAP also recommends that infants should be placed on a firm sleep surface (e.g., mattress in a safety-approved crib) covered by a fitted sheet with no other bedding or soft objects to (Moon et al., 2016). However, previous research has indicated that parents have different interpretations of the term “firm” (Ajao et al., 2011). The AAP uses the term “firm” to reference a surface that maintains its shape and will not indent or conform to the shape of the infant’s head when the infant is placed on the surface (Task Force on Sudden Infant Death Syndrome, 2016).

### **Soft bedding/Crib bumpers**

Several publications have documented that soft bedding increases the risk of SIDS (Ajao, Oden, Joyner, & Moon; Flick et al., 2001; Hauck et al., 2011). Thus, in 2011 AAP expanded their recommendations informing caregivers that they should avoid soft bedding and soft sleeping surfaces. Many parents perceive that the infant will sleep more comfortably if placed on a soft surface or that the soft bedding will prevent injury (e.g., from bumping into crib railings or falling off the bed or sofa) (Ajao et al., 2011; Hauck et al., 2011). After conducting focus groups and interviews with 83 black mothers to determine the use of soft bedding in infant sleep environments, Ajao et al. found that mothers were more likely to use soft bedding to enhance infant comfort despite recommendations to place infants in empty cribs. Thus, these findings indicate that unfortunately, many parents are unaware may unknowingly place their infants at greater risk when they place these items in the sleeping environment (2011).

## **Bed Sharing**

Approximately 50% of SIDS occurrences transpire when infants are sharing a bed, sofa, or sofa chair with another person (Kinney & Thach, 2009). Parents choose to bed share for multiple reasons, including convenience of feeding, space considerations, safety concerns, cultural traditions, and enhanced sleep of the infant (Hauck et al., 2011; Keene Woods et al., 2015). However, sharing an adult bed (bed sharing) or other sleep surfaces with infants has been found to increase the risk of SIDS (Carpenter et al., 2013; Louise Flick et al., 2001; F. R. Hauck, S. M. Herman, M. Donovan, S. Iyasu, C. M. Moore, et al., 2003; Moon et al., 2016; Tappin et al., 2005). It is important to note that previous research has shown that the risk of SIDS while bed sharing is only significant when sharing the bed with bedmates other than the mother or with bedmates in addition to the mother (Flick et al., 2001; F. R. Hauck, S. M. Herman, M. Donovan, S. Iyasu, C. M. Moore, et al., 2003). Despite this finding, Hauck et al. (2003) rejects the idea that bed sharing with parents is a protective factor for SIDS.

In their PubMed and Medline meta-analysis on the influence of bed sharing on SIDS, Vennemann et al. (2012) analyzed 11 case-control studies and found that when an infant routinely bed shared with their mother, the risk associated with SIDS was not significant. It is important to note that when bed sharing is not routinely practiced there appears to be an increased risk of SIDS. In their analysis, Vennemann et al. (2012) discovered that on the last night when bed sharing was not routine the risk of SIDS was statistically significant. Another important finding from their meta-analysis revealed that when they analyzed studies that included data on maternal smoking, the SIDS risk rises. In addition to maternal smoking, the literature indicates that there are several bed sharing scenarios that can potentially increase an infant's risk of SIDS. For instance, when there are multiple bed sharers present the risk of SIDS



further increases (R. G. Carpenter et al., 2004; Hauck et al., 2003; Scheers et al., 2003). In their Chicago Infant Mortality Study, Hauck et al. (2003) found that the SIDS risk associated with bed sharing was primarily found when the infant was sleeping with people other than their parents.

Multiple research studies have found that African American mothers are more likely to bed share (Gaydos et al., 2015; Joyner et al., 2010; Moon & Omron, 2002; Oden, Joyner, Ajao, & Moon, 2010; Ostfeld et al., 2006). Consequently, most bed sharing deaths occur in black infants (Hauck et al., 2011). Black infants who die from SIDS are more than 1.5 times as likely to have been placed on a sleep surface other than a crib, such as an adult bed, sofa, or waterbed (Hauck et al., 2011). Black infants who bed share are significantly more likely than Hispanic infants to be exposed to parental smoking (Hauck et al., 2011).

Even more alarming is falling asleep with an infant in a chair or a sofa, as previous research studies have shown that sharing a sofa with an infant increases the risk of SIDS (Ball & Volpe, 2013; Blair et al., 1999). It has been assumed that much of the risk associated with sleeping on a sofa results from the soft cushioning and sloping surface of sofas (Rechtman, Colvin, Blair, & Moon, 2014). In recent years there has been growing interest around the subject of bed sharing and breastfeeding. Bed sharing helps facilitates breast feeding at night mothers with has been shown to be a protective factor against SIDS; however, mothers who breastfeed are more likely to bed share than mothers who don't breastfeed (Keys & Rankin, 2015).

For decades, researchers have debated if the benefits of breastfeeding outweigh the risks of bed sharing. Bartick & Smith (2014) attributed increases to occurrences of parents falling asleep with their infants in unsafe locations, such as a sofa or recliner, to the AAP's recommendation against bed sharing. Specifically, Bartick & Smith (2014) referenced the results of a 2010 survey in which 44% of mothers reported falling asleep with their infants in a location

other than a bed. The study also suggested that parents who intentionally bed share are less likely to have adverse effects (Bartick & Smith, 2014).

Although the AAP maintains their stance on the risks of bed sharing, in the most recent AAP recommendations released in 2016 the AAP broadened their guidance to address bed sharing while breastfeeding. The new recommendations state that “infants who are brought into the bed for feeding or comforting should be returned to their own crib or bassinet when the parent is ready to return to sleep” (Moon et al., 2016, p. 5). There is a growing body of evidence that demonstrated that room sharing without bed sharing is associated with a reduced risk of SIDS (Blair et al., 1999; R. Carpenter et al., 2004; Moon, Horne, & Hauck; Tappin et al., 2005).

### **Pacifiers**

Several studies have demonstrated that the use of a pacifier at onset of sleep may reduce the risk of SIDS by as much as 90%, even when the pacifier falls out of the mouth after the infant falls asleep (Alm, Wennergren, Möllborg, & Lagercrantz, 2016; Carlin & Moon, 2017; Franco et al., 2000; Moon, Tanabe, Yang, Young, & Hauck, 2012). This protection is thought to be attributed to increased arousability, increased sleeping blood pressure, and increased low frequency heart rate variability and decreased high frequency heart rate variability, indicating improved autonomic control (Yiallourou et al., 2014).

Moon et al. (2012) analyzed the data from the Chicago Infant Mortality Study and concluded that pacifier use may offer increased protection when factors associated with an increased risk of SIDS, including when the infant was sleeping in the prone/side position, bed sharing, and when soft bedding was present. Despite this fact, study findings suggest that parents are less knowledgeable about the protective nature of pacifiers. A recent study by Salm Ward,

McClellan, Miller, and Brown (2018) revealed that less than 10% of study participants correctly identified pacifier use as a protective factor for SIDS.

### **Smoking**

In the past 10 years, SIDS research has provided ample support for the assertion that, infants born to mothers who smoked during pregnancy had an increased risk of SIDS compared with infants born to women who had not smoked during pregnancy (Ball & Volpe, 2013; Liebrechts-Akkerman et al., 2011; Wisborg et al., 2000). The AAP recommends that mothers should not smoke during pregnancy or after the infant's birth (Moon et al., 2016). The literature has also found that infants born to mothers who smoked during pregnancy are three times more likely to die of SIDS than those born to mothers who did not smoke during pregnancy (Tong et al., 2005). Along similar lines, infants who are exposed to secondhand smoke in the home are two times more likely to die from SIDS (Tong et al., 2005). McMartin et al. (2002) compared lung concentrations of nicotine and cotinine in cases of SIDS and found that infants who died from SIDS have a higher nicotine concentration in their lung tissue compared with infants who did not die from SIDS. In addition to highlighting best practices related to sleep location and sleep position the recommendations offered guidance on prenatal care, overheating, infant immunizations and tummy time (Moon et al., 2016).

### **Maternal Trust**

Trust is a critical component of an effective patient-physician relationship. Trust also plays a major role in adherence to health care recommendations. Trust can be understood as individuals seeing one another as competent, responsible, caring, tactful and ethical (Jones, Carson, Bleich, & Cooper, 2012). Existing research demonstrates that for mothers, trust in their

child's medical providers, such as nurses and physicians, is associated with improved compliance with a few health promoting behaviors. Hwang et al. (2016) found in their study that 80 % of mothers trusted doctors while only 35 % trusted nurses for advice on infant sleep position. Their study also revealed that prevalence of trust varied by the topic of advice given with trust being greater for advice on sleep position, feeding, and vaccination and lower for bed sharing and pacifier use (Hwang et al., 2016). Trust in health care professionals is also associated with increased adherence health care recommendations (Hwang et al., 2016).

In a study of African American mothers with infants between the age of 0 to 6 months, Coleman (2009) found that when mothers encounter nurses with a positive and supportive demeanor they are more likely to adhere to nurse recommendations. This discovery revealed that an association exists between mothers' confidence and trust in their nurse and increased adherence to infant safe sleep recommendations. Another notable finding from Coleman's study was that first time mothers in particular reported seeking information about infant sleep positioning from grandmothers. Furthermore, some participants viewed the nurses recommendations as secondary to the grandmothers recommendations about infant sleep positions and environments (Coleman, 2009).

As reported by Coleman (2009), family and friends have a powerful influence on a mother's choice of sleep position. Grandparents, in particular, play an important role when it comes to influencing a mother's decision to follow infant safe sleep recommendations. When a grandmother is in the home, infants are more likely to be placed in the prone sleeping position (Aitken et al., 2016; Colson et al., 2005; Gaydos et al., 2015). Although grandmothers usually want to offer advice and help their children become good parents, they may be sharing antiquated recommendations (Caraballo et al., 2016; Chesser et al., 2019). The role of

grandparent influence is also worth noting. In examining the reasons mothers chose not to follow the SIDS prevention recommendations, Oden (2010) found that the, “prone sleeping position has also been linked to a grandparent in the home or if the infant is the first-born child.”

Caraballo et al. (2016) conducted focus groups with 43 adolescent mothers at high school daycare centers throughout Colorado and they found that most mothers reported receiving conflicting information related to parenting. Discrepancies occurred most frequently between medical providers and participants’ own mothers. Numerous mothers shared they had received advice that conflicted with their intuition, especially with regards to bed sharing. In a study of African American mothers, many of the mothers expressed that they did not understand the connection between sleep position and SIDS and did not see this link as being a plausible one (Moon, Oden, Joyner, & Ajao, 2010).

When faced with conflicting information, previous research indicates that mothers stated they were most likely to listen to their own mothers, while a few stated they would consider their pediatrician’s advice first (Caraballo et al., 2016). Some mothers reported they were more likely to trust people with children of their own, whether medical provider, friend, or family member. A few mothers explicitly stated that they were less likely to trust their child’s pediatrician if the doctor did not have children (Caraballo et al., 2016).

## **Health Literacy**

Little research has focused on the relationship between infant caregiver health literacy and adherence to following infant safe sleep recommendations. Up until this point, most studies have focused on the relationship between parental knowledge of safe sleep practices and adherence. According to the American Medical Association, 90 million people in the United States struggle with health literacy (Heerman et al., 2014). Health literacy is defined as the

degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Heerman et al., 2014).

Most adults read at an eighth-grade level, and 20 percent of the population reads at or below a fifth-grade level; however, health care materials are usually written at a 10th-grade level (Safeer & Keenan, 2005). Low health literacy can result in difficulty accessing health care, following instructions from a physician, and taking medication properly (Safeer & Keenan, 2005). A high prevalence of non-adherence to recommended injury prevention behaviors is common across racial/ethnic categories for caregivers of infants among a diverse sample of families from low-SES backgrounds. To adequately care for an infant, caregivers must be able to read and comprehend information such as, food and prescription labels, doctor's orders, and other health materials (PHLAT, 2010). Despite the risk factors associated with low health literacy, there are limited studies that have focused on the role of the caregiver's health literacy.

### **Barriers to Facilitating Infant Safe Sleep Recommendations**

Barriers to adhere to infant safe sleep recommendations are numerous. For one, some parents don't understand the rationale for placing an infant back to sleep for sleep (Y Moon et al., 2016). Another challenge is that some parents feel their infant is immune to SIDS. Misinformation about SIDS or a lack of knowledge about SIDS ultimately may be responsible for some mothers' inaccurate beliefs about the dangers of certain sleep practices. In their qualitative study of African American mothers, Colson et al. (2005) found that several participants possessed a lack of knowledge about SIDS and SIDS risk factors. Some mothers believed that SIDS, which is commonly referred to as "crib death" could only occur if the baby was sleeping in a crib (Eve R Colson et al., 2005).

In the same vein, Mosley, Stokes, and Ulmer (2007) found that a surprising number of focus group participants believed that “crib death” can only take place in a crib. Another study conducted by Herman et al. (2015) revealed that some mothers believe SIDS is a disease or syndrome and therefore, one can’t protect their infant from SIDS. These results demonstrate that there is still a need to dispel myths about SIDS and educate parents about infant safe sleep practices (Chung-Park, 2012). In addition, several studies reveal that parents do not believe that their behavior except for vigilance can affect SIDS risk because they view SIDS as a random act of God (Fern R Hauck et al., 2011; Moon, Oden, Joyner, & Ajao, 2010). As discussed earlier, grandmothers play a critical role influencing infant safe sleep practices (M. E. Aitken et al., 2016; Brenner, Simons-Morton, Bhaskar, & et al., 1998; L. Flick et al., 2001; A. Mathews et al., 2016; Moon et al., 2004; Moon & Omron, 2002). In a recent qualitative study of healthcare providers, participants identified grandmothers as being the biggest barrier to getting young mothers to follow infant safe sleep recommendations (Thornhill-Scott, Redmond, Dong, & Ablah, 2016).

There may also be extenuating circumstances that make performing the behavior challenging. Families facing financial hardships or who live in dangerous conditions, may also face certain barriers to following infant safe sleep recommendations. In a qualitative study of African American parents of infants under 6 months old, mothers living in economically disadvantaged households expressed concerns about environmental dangers, particularly vermin, random kidnapping, and stray gunfire (Hackett & Simons, 2013; Joyner, Oden, Ajao, & Moon, 2010; Lathen, 2009). In the same study, mothers also cited a lack of adequate space and the unavailability of a crib as reasons for both room sharing and bed sharing. Unless these barriers

are overcome, mothers and caregivers may continue not following infant safe sleep recommendations.

Eldredge, Markham, Kok, Ruiter, and Parcel (2016) define facilitation as making changes in the environment to make desired behaviors easier to achieve. Numerous infant sleep interventions have explored the effectiveness of providing participants with resources (e.g., cribs, onesies, wearable blankets) to support following established infant safe sleep recommendations (Ahlers-Schmidt et al., 2014; Carlins & Collins, 2007; Hauck et al., 2015; Salm Ward et al., 2018). For some families, the items they receive from these interventions are their only resource. This is evident in a recent infant safe sleep education and crib distribution intervention, in which researchers reported that approximately 36% of participants stated that prior to receiving the portable crib they had planned on bed sharing (Salm Ward et al., 2018).

### **Baby Boxes**

In the last few years there has been a growing interest in the domestic use of baby boxes and several states, including New Jersey, Ohio, and Alabama, have started providing pregnant women with baby boxes (Ahlers-Schmidt et al., 2017). Baby boxes are cardboard boxes that come equipped with a mattress and it can be used for infant sleep (Ahlers-Schmidt et al., 2017). Baby boxes have been used in Finland since 1938 (Ahlers-Schmidt et al., 2017; Y Moon et al., 2016). Originally, the baby boxes were only distributed to low-income families (Lee, 2013). However, starting in 1949 the Finland government began providing all expectant mothers who receive a prenatal exam during the first four months of pregnancy with a baby box filled with baby supplies and baby clothes (Lee, 2013; Y Moon et al., 2016). In the 1930s, Finland was a very poor country that experienced high rates of infant mortality, 65 deaths per 1,000 live births (Lee, 2013).



Now, Finland has one of the lowest infant mortality rates in developed countries (Ahlers-Schmidt et al., 2017). However, Bartick and Tomori (2017) argue that the boxes are not solely responsible for Finland's low mortality rates and that other factors such as universal health care, social safety nets, and paid maternity leave policies contribute to low infant mortality rates. Despite the recent interest, to date, there have been no empirical investigations into the use of baby boxes in the United States.

### **Parental Attitudes Towards Baby Boxes**

Ahlers-Schmidt et al. (2017) conducted a semi-structured interview with 28 women about their knowledge and opinions of baby boxes. Prior to the interview, most interviewees (64%) were not familiar with baby boxes. The researchers noted that two themes emerged, (1) that baby boxes may be beneficial for families who cannot afford a traditional crib and (2) that based on the success the boxes had in Finland the boxes may be a worthwhile resource. Within the themes noted above, Ahlers-Schmidt et al. (2017) reported that 4 subthemes emerged about the boxes: (1) portable, (2) compact, (3) affordable, and (4) decorative. There were some negative themes that emerged as well. For example, some interviewees asked, "Why is your baby in a box?" and others stated that baby boxes might be appropriate, "for someone in need, it might be a good situation." Thus, some interviewees remarked that the baby box was only appropriate for people with a lower SES. Several interviewees expressed concerns about the box's safety, including hazards (such as pets or other children) getting into the box, and the potential for people to kick or trip over the box, especially at night.

## **Potential Concerns**

As previously mentioned, limited studies have investigated the use of baby boxes. Nonetheless, among the available evidence support for the use of baby boxes has been mixed. Bartick and Tomori (2017) argue that baby boxes may disrupt breastfeeding. It is important to note that their criticism is not unique to baby boxes. Researchers have raised similar concerns about the impact infants sleeping in separate surfaces has on breastfeeding (Melissa Bartick & Smith, 2014).

*Safety.* The extent to which baby boxes presents a risk to an infant’s safety is unknown. The AAP recommends that infants be placed to sleep in a crib, bassinet, or play yard that meets the safety standards of the Consumer Product Safety Commission (CPSC) (Moon et al., 2016). AAP contends that for some families who may not be able to afford a crib or who may have concerns about placing infants in a crib, it may be more feasible to use a portable crib or smaller sleep surface (Moon et al., 2016). Baby boxes are compact and portable. However, currently there are no CPSC standards for baby boxes and therefore, the AAP has not provided a recommendation on the use of baby boxes. A review of infant deaths involving a playpen or portable crib revealed that between 1999 and 2004, 21 infants died in a portable crib or playpen (Jackson & Moon, 2008). This finding reinforces the importance of providing caregivers with infant safe sleep education before providing any sleep surface. Furthermore, the guidance that AAP has outlined regarding infant sleep environments, “use a firm and snug-fitting crib mattress, avoid soft objects and loose bedding” in the crib should be followed despite the sleep surface, including baby boxes (Jackson & Moon, 2008; Moon et al., 2016).

## **Theoretical Framework**

This study is primarily guided by the Theory of Planned Behavior (TPB) (Icek Ajzen, 1991), which is an extension of the Theory of Reasoned Action (TRA) (Fishbein & Ajzen, 1975). The TPB suggests that intention is strongly associated with behavior change, with three major factors influencing intention to perform or change a specific behavior: attitudes, subjective norms, and perceived behavioral control. The TPB argue that behavioral intention is the most important determinant of behavior (Ramer & Glanz, 2005). Sheina, Sarah, and Paschal (1997) state that intention is conceptualized in the TPB as a summary of the cognitive and affective mechanisms through which attitude, subjective norm, and perceived behavioral control direct future behavior (p. 19).

In the TPB, attitudes refer to an individual's evaluation of the perceived costs and benefits of participating in the behavior. Subjective norms refer to the perceived expectations of significant influencers concerning participating in the behavior. Finally, perceived behavioral control is related to the amount of control an individual perceives to have over participating in the behavior. Together, these factors contribute greatly to an individual's intention of carrying out the behavior. Thus, the more favorable a person's attitude is toward behavior and subjective norms, and the greater the perceived behavioral control, the stronger that person's intention will be to perform the behavior (Ajzen, 2006; Mimiaga, Reisner, Reilly, Soroudi, & Safren, 2009). Ajzen (2006) posits that when given a sufficient degree of actual control over the behavior, people are expected to carry out their intentions when the opportunity arises.

Behavioral control is an important factor to consider, as many individuals intend to perform a particular behavior; however, there may be additional barriers or circumstances that make execution of the behavior difficult (Ajzen, 2006). Behavioral control is similar to self-

efficacy (Bandura, 1978) in that it depends on how difficult it is going to be to participate in the behavior. Ajzen (2006) states, “Subjective norms are determined by beliefs that specific referent individuals or groups approve of the behavior (belief strength) and motivation to comply with those referents” (p. 4). Beliefs represent information people have about a behavior, including its likely consequences, the normative expectations of others, as well as the likely impediments to its performance (Ajzen, 2006).

It may be easier to produce behavior change by providing individuals with information designed to generate new ideas instead of changing existing beliefs (Ajzen, 2006).

### **Additional Constructs**

***Attitudes.*** Overwhelming evidence suggests that mothers make decisions about their infants’ sleep locations and positions based on their perceptions of their infants’ physical and emotional comfort and perceptions of what was safe, effective, and convenient in meeting the needs of their infants while also meeting their own need for rest (Taiwo I Ajao et al., 2011; Canter et al., 2015; Colson et al., 2005; B. L. Joyner, R. P. Oden, T. I. Ajao, & R. Y. Moon, 2010). Researchers cite several factors contributing to the lack of compliance of infant safe sleep recommendations such as, perceived safety, comfort of mother and child, culture and conflicting information from other family members (L. M. Gaydos et al., 2015). Adolescent mothers, in particular, are more likely to rely on their underlying attitudes, beliefs, and instincts more than knowledge or advice from medical providers to inform their decisions.

***Knowledge.*** Knowledge is an important prerequisite for any behavior change (Bandura, 2004). Bandura (2004) contends that when people lack knowledge about how their lifestyle choices affect their health, they have little reason to put change routine habits that might be detrimental. SIDS myths continue to persist and may be responsible for inaccurate beliefs about

the dangers of certain sleep practices. In their qualitative study of African American mothers, Colson et al. (2005) found that several participants possessed a lack of knowledge about SIDS and SIDS risk factors. Some mothers believed that SIDS, which is also referred to as “crib death” could only occur if the baby was sleeping in a crib. Another study revealed that some mothers believe SIDS is a disease or syndrome and therefore, one can’t protect their infant from SIDS (Herman et al., 2015). These results demonstrate that there is still a need to dispel myths about SIDS and educate parents about infant safe sleep practices (Chung-Park, 2012).

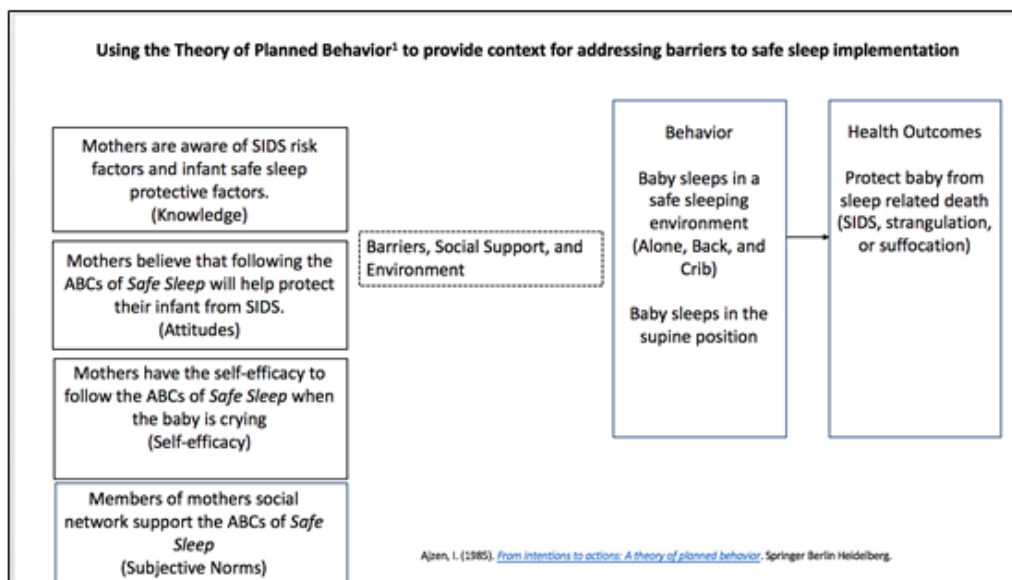
Most SIDS research has focused on the relationship between parental knowledge of safe sleep practices and adherence instead of low parental health literacy and adherence. Evidence suggests that infants of less educated mothers are more likely to die from SIDS than infants of more educated mothers (Pickett, Luo, & Lauderdale, 2005). This finding may be attributed to the fact that less educated mothers may not fully understand the AAP’s safe sleeping recommendation and as result are less likely to follow the recommendations. Conversely, other studies have shown that African American mothers of various socioeconomic statuses understand the recommendations, but deliberately choose not to follow them. Thus, perhaps the recommendations aren’t written at appropriate reading levels, but lack cultural relevance.

***Self-Efficacy.*** Bandura (1986) defines self-efficacy as one's belief in one's ability to succeed in specific situations or accomplish a task. For this reason, self-efficacy is a key determinant in health promoting behaviors. More recent evidence suggests that African American mothers report having low self-efficacy regarding SIDS risk reduction (A. Mathews et al., 2016b; Robida & Moon, 2012). To the contrary, the mothers reported having higher self-efficacy regarding suffocation prevention, although the risk factors for SIDS and suffocation are similar (A. Mathews et al., 2016b). These results reveal that mothers may not be confident in

their ability to protect their infants from SIDS. Likewise, some mothers may bed share because they do not have the self-efficacy needed to handle or soothe their infants when they start crying (Aslam, Kemp, Harris, & Gilbert, 2009; Chianese, Ploof, Trovato, & Chang, 2009; Culver, 2008; Hackett & Simons, 2013; McKenna & Volpe, 2007; Rowe, 2003).

In a qualitative study with primary caregivers of infants ages 1 to 6 months who regularly bed share, researchers reported that parents perceived that their infants fell asleep easier, cried less, and woke up less frequently during the night when they slept with the parent compared to when the infant slept in a separate location (Chianese, Ploof, Trovato, & Chang, 2009). There are multiple factors that may contribute to a mother's low self-efficacy towards following infant safe sleep recommendations. However, enhanced education that focuses on protective and risk factors for SIDS and provides tips on how to soothe infants during bed time might increase confidence in following established infant safe sleep recommendations among mothers.

As demonstrated in Figure 1., this study aims to determine the attitudes that mothers have towards infant safe sleep recommendations, the subjective norms, such as the opinions of grandparents and partners about SIDS and infant safe sleep practices, which may influence her decision to follow infant safe sleep recommendations, and her perceived control of implementing infant safe sleep recommendations, particularly when her baby cries. In addition, we will evaluate mothers' knowledge of SIDS and explore the influence of barriers, social support, and environmental characteristics. Knowledge of SIDS refers to how knowledgeable the mother is about SIDS and risk and protective factors for SIDS. Barriers and environmental characteristics refer to external circumstances that may influence a mothers' decision to follow infant safe sleep recommendations.



**Figure 2. Using the Theory of Planned Behavior to Provide Context for Addressing Barriers to Safe Sleep Implementation**

### Cultural Adaptation Models

Because infant sleep related deaths disproportionately affect ethnic minorities in the United States, infant safe sleep interventions should be tailored to these audiences. To do so effectively, intervention developers must implement an audience-centered planning process that provides a foundation for the development of culturally innovative interventions. Cultural adaptation involves a planned, organized, iterative, and collaborative process that often includes the participation of persons from the targeted population for whom the adaptation is being developed (Castro et al., 2010).

Culture is a complex phenomenon that encompasses language, shared knowledge, behaviors, and cognitive constructs such as thoughts, beliefs, and norms (Dinos, 2015). Even when culture is not a conscious consideration in providing interventions and services, it is a powerful force that often influences how a client or participant responds to an intervention and subsequent outcomes (Substance Abuse and Mental Health Services Administration [SAMHSA],

2014). For this reason, intervention developers who are aware of how culture affects their own views, as well as clients or participants are better suited to work with participants. In addition to understanding how culture influences decisions and behaviors, intervention developers and public health practitioners must also understand that cultural disconnects may exist for people with the same ethnicity or race. Therefore, intervention developers must take steps to understand the shared values and beliefs, as well as the disconnects that exist among people of a culture.

Cultural adaptations may vary greatly between interventions that make minor to no adaptations to the original evidence-based intervention (EBI) to interventions that completely reject the original EBI in favor of an innovative culturally grounded approach that is developed in collaboration with members of the target audience (Castro et al., 2010). F. Marsiglia and Booth (2014) write that, “a culturally grounded approach starts with assessing the appropriateness of existing evidence-based interventions and adapting when necessary, so that they are more relevant and engaging to clients from diverse cultural backgrounds, without compromising their effectiveness” (p. 1-2).

### **Approaches to Adapting EBIs**

Several frameworks, models and guidelines have been developed to guide the cultural adaptation of an intervention (Goldman, 2013). Models usually provide a design for intervention developers to replicate, whereas frameworks provide a frame of reference or share an approach and guidelines provide specific recommendations (Goldman, 2013). In their Cultural Sensitivity Framework (CSF), Resnicow and colleagues (2000) specify that cultural sensitivity in developing tailored prevention interventions consists of two dimensions: surface structure adaptations and deep structure adaptations. Surface structure adaptations consist of activities



such as, matching program materials and messages to the characteristics of the target population (e.g., language, locations, and people).

Whereas, deep structure adaptations refer to incorporating elements that influence the behavior of the target group (e.g., sessions with specific content, which paid attention to large sibling groups, emotion control, racial socialization, cultural and contextual influences on parenting, and communication training). Resnicow et al. (2000) recommend using a mixed methods research approach that consists of conducting quantitative and qualitative research; reviewing existing databases; and collecting new data. It is assumed that by addressing both the surface and deep structure aspects that intervention participants will be more likely to engage in the intervention and that the intervention outcomes are more likely to be met (F. Marsiglia & Booth, 2014).

Domenech-Rodríguez and Wieling's (2009) Cultural Adaptation Process Model (CAPM) expands on the ecological validity model (G. Bernal, Chafey, & Domenech Rodríguez, 2009). The CAPM model consists of three phases: (1) setting the stage, (2) initial adaptations, and (3) adaptation iterations (Domenech-Rodríguez & Wieling, 2004). During the first phase, intervention developers and cultural specialists should establish a collaboration. Collaborators should review the relevant literature to examine intervention fit for the targeted audience. Collaborators should also conduct meetings with community leaders to identify intervention priorities. Lastly, Domenech-Rodríguez and Wieling (2004) recommend that collaborators should gauge the needs of the community. The second phase of the intervention consists of identifying appropriate outcome measures and a two-step process that outlines the adaptation of the intervention. In the third phase of the intervention, intervention developers determine

whether additional adaptations are needed and whether the original intervention will be improved by the adaptations.

Nastasi et al. (2000) introduced the Participatory Intervention Model (PIM) with the goals of integrating theory and research into the development of culture or context specific interventions and to promote ownership and empowerment among stakeholders. PIM is a nonlinear and iterative process that fosters the social construction of interventions and empowerment of participants (Nastasi et al., 2000). Nastasi et al. (2000) argue that as a result of ownership and empowerment, stakeholders come to view the intervention as their own creation and take responsibility and control over the intervention process.

In addition, Nastasi, Moore, and Varjas (2004) introduced the Participatory Culture-Specific Intervention Model (PCIM). PCIM is a multiphase, and typically multiyear, approach to program development and evaluation that involves an iterative research intervention process using mixed-methods research and participatory consultation (Nastasi et al., 2004). The phases include articulating the researcher's conceptual framework based on existing theory, research, practice, and policy; learning the culture; establishing partnerships with key stakeholders; identifying broad program goals; conducting formative research on key constructs (e.g., psychological well-being, culturally valued competencies); developing culture-specific or local theory (conceptual model); culture-specific program design, based on formative research and local theory; program implementation and evaluation; sustainability and capacity building; and dissemination and translation.

These models and frameworks share many key features. For one, they all recommend incorporating the expertise of community stakeholders to inform the adaptations. Two, they also stress the importance of using formative research to inform the intervention using performance

evaluations to determine the effects of the adapted intervention (Baumann et al. 2015; Domenech Rodriguez et al. 2011). Next, they all point out that there is a role for both quantitative and qualitative methods (also known as mixed methods research) during multiple phases of the development process.

## **Conclusion**

While much literature exists on the risk and protective factors for SIDS, studies that explicitly focus on the reasons why African American mothers are less likely to follow infant safe recommendations are lacking. However, based on the available evidence health promotion practitioners need to better understand African American mothers and grandmothers' perceptions and insights regarding infant safe sleep recommendations and current infant safe sleep interventions to develop more effective and culturally relevant infant safe sleep interventions. It is also evident that future interventions should focus on grandmothers and other caregivers.

## CHAPTER 3

### METHODS

The purpose of this qualitative study was to explore perceptions of infant safe sleep interventions among low-income African-American mothers and grandmothers to develop recommendations for the development of a culturally tailored infant safe sleep intervention to increase adherence to evidence-based infant safe sleep recommendations. This study was guided by the following specific aims:

1. Describe African American mothers and grandmothers' beliefs and perceptions of infant's risk susceptibility for an infant sleep-related death.
2. Describe African American mothers and grandmothers' attitudes toward established infant safe sleep recommendations.
3. Describe African American mothers and grandmothers' perception of baby boxes for use of an infant sleep environment.

Based on the constructs in the TPB (Ajzen, 1991), the greater a caregiver's intent to follow the infant safe sleep recommendations, the greater the likelihood that they will adhere to established infant safe sleep recommendations. Therefore, intent to follow infant safe sleep recommendations derives from one's personal beliefs about the positive and negative outcomes of following infant safe sleep recommendations (*attitudes*), beliefs about whether grandmothers or other partners will approve or disapprove of following the infant safe sleep recommendations (*subjective norms*) and beliefs about whether they can perform infant safe sleep recommendations (*self-efficacy*).

To develop recommendations for a culturally tailored infant safe sleep intervention for African American mothers and grandmothers, this study was conducted using a qualitative research design. Stake (1995) posits that qualitative approaches are particularly useful when the research questions require exploration. The purpose of the focus groups was to obtain African American mothers and grandmothers' perceptions regarding evidence-based infant safe sleep recommendations, existing infant safe sleep interventions, the use of baby boxes for infant sleep environments, and the influence of subjective norms were used to collect data from participants. This information was used to inform recommendations for the infant safe sleep intervention.

Beck, Trombetta, & Share (1986) define a focus group as, "an informal discussion among selected individuals about specific topics" (p.73). Focus groups are one of the most useful techniques to explore the depth and nuances of participants' beliefs and have been found to be effective with minorities (Fern & Fern, 2001; Kitzinger, 1995). Focus groups typically consist of one or more group discussions, in which participants focus collectively upon a topic or issue that are commonly presented to them through a set of questions (Wilkinson, 1998). Discussions between focus group participants are usually audiotaped (sometimes videotaped) and transcribed, constitute the data, and conventional techniques of qualitative analysis are then employed (Wilkinson, 1998).

Within qualitative research, there are five major qualitative approaches to inquiry: narrative research, phenomenology research, grounded theory research, ethnographic research and case study research (Creswell and Poth 2017). This study is guided by phenomenology. Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences (van Manen 1990). Crotty (1998) declares that researchers need to break

with inherited understandings to obtain a fuller meaning of phenomena. Palmer, Larkin et al. (2010) define interpretative phenomenological analysis (IPA) as an approach to qualitative research that is concerned with understanding people's experiences of the world and of themselves. Although, most IPA studies are semi-structured interviews, for some studies the group dynamics of focus groups add something unique which would otherwise have been missed (Flowers, 2001). The collaborative nature of the focus groups offers an advantage over one-on-one individuals because it offers multiple voices. Therefore, using an IPA approach, this study aims to identify previously overlooked or hidden factors influencing African American female caregivers' decision to follow infant safe sleep recommendations by capturing the additional insights from mothers and grandmothers.

### **Focus Group Facilitation**

Two 90-minute focus groups with 5 to 6 participants each were held. The purpose of the focus groups was to obtain feedback on existing infant safe sleep consumer materials. The focus group participants consisted of African American mothers and one African American grandmother. The focus group discussion guide was developed using the TPB (I. Ajzen, 1991) (see APPENDIX A).

It is important to understand what elements of the infant safe sleep recommendations focus group participants deemed to be unacceptable, particularly as it pertains to the ability of the target population to carry these activities or recommendations out. Therefore, questions were asked to query participants to identify factors that may make it difficult for African American mothers and grandmothers to follow the proposed infant safe sleep recommendations. As such, focus group participants reviewed the NICHD's *Safe Sleep for Your Baby* brochure (National Institute of Child Health and Human Development, 2015) (See APPENDIX B) and provided

feedback on what elements or messages would motivate them to follow the recommendations and what barriers or messages would prevent them from following the recommendations. Thus, the results from the focus groups were transcribed, analyzed, and recommendations for a culturally tailored infant safe sleep intervention materials were developed.

### **Selection of Participants**

Purposive and snowball sampling was used to identify focus group participants. Patton (2002) posits that purposeful sampling allows qualitative researchers to study information-rich cases to yield insights and in-depth understanding rather than empirical generalizations. Mothers were participants in the Healthy Start Program which serves pregnant and parenting women who are considered most at-risk for infant mortality with a child under 2 years old. The focus group eligibility for African American mothers consisted of pregnant women and mothers who had an infant 12 months or younger at time of recruitment and demonstrate financial need (based on receipt of services through Women, Infants, and Children Nutritional Program; Medicaid, or Temporary Assistance for Needy Families). Grandmothers, sisters or aunts who regularly take care of an infant 12 months or younger, and who are at least 40-years old were also actively recruited.

Focus group participants were recruited via flyers (see APPENDIX C) at the Center for Black Women's Wellness in Fulton County, Georgia. African American mothers and grandmothers who responded to the flyer were invited to participate in the focus groups.

### **Procedures**

Demographic data was collected from participants during an exit survey at the end of the second focus group. At the end of each focus group, participants received a \$50 gift card to

Walmart. Participants who referred other eligible participants received an additional \$15 gift card to Walmart.

Twenty-one individuals expressed interest in participating in the focus groups. One of the CBWW staff members provided the study team with a list of participants and their telephone numbers. A member of the research team called all interested parties to confirm participation and provide details regarding the focus group time and location. The day before the focus groups, research team members sent out confirmation text messages to the participants.

Focus groups were conducted in a classroom at the Center for Black Women's Wellness in Atlanta, GA. Prior to the start of each focus group, I passed out two consent forms (APPENDIX E) to each participant. The consent form disclosed details about the nature of the study, the voluntary nature of the focus group and participants' rights regarding participation. I read the consent form out loud at each focus group. I then asked participants if they had any questions and concerns and if not, please sign both copies and return one to me. After obtaining permission, I conducted audio recorded focus groups in which participants were asked questions (see APPENDIX A) that focused on infant sleep position, infant sleep environment, as well as factors influencing sleep location decisions from previous published studies (Gaydos et al., 2015; Joyner et al., 2010). I also brought a baby box and a doll for a demonstration and asked participants to share their thoughts on baby boxes.

## **Data Analysis**

The Statistical Package for the Social Sciences (IBM SPSS, Version 24) was used to analyze demographic data. Both focus groups were audio-recorded and professionally transcribed using the Trint Transcription Service. Palmer et al. (2010) recommends that when



more than one focus group has taken place, the researcher should, “Integrate work done with each to build up an overall analysis of the topic under investigation. Data should be checked to ensure sufficient homogeneity between focus groups to allow for successful integration” (p.100). Using an 8-step protocol developed by Palmer et al. (2010) (see APPENDIX D), transcripts from both focus groups were examined to identify emergent themes and shared experiences, as well as extract meanings.

### **Subjectivity Statement**

As a doctoral student researching factors influencing African American mothers and grandmother’s decisions to follow the infant safe sleep recommendations, I have had many life experiences that have shaped my view of infant health disparities among African American children and you. Prior to earning my master’s degree in health and medical journalism, I developed programs for children and youth in Fulton County government. That experience piqued my interest and inspired me to cover stories that focused on maternal and infant health. As a student journalist, I discovered that an alarming number of infants were dying on SIDS in Georgia. After graduating from my master’s program, I accepted a fellowship at CDC. From my experience working at CDC, I learned more about prevention strategies related to SIDS.

Although I rely heavily on these experiences, as I am not a parent yet, I am keenly aware that these experiences need to be bracketed to study the phenomenon from a fresh perspective. Furthermore, I recognize that my exposure to certain public health classes, public health professionals, conferences, and experiences has assuredly predisposed me in many ways to trivialize the adherence of infant safe sleep recommendations. I realize that deferring to my practitioner experience will not serve me as well in this study.

While I acknowledge that I'm passionate about infant sleep related deaths, I recognize that it is important to step back and gain a deeper understanding why families choose to follow or not follow infant sleep recommendations. I want to learn about how these women think and feel, and discover what barriers are in place that may be influencing their decisions. Ultimately, I want to know how we as public health professionals can help include and empower African American mothers and grandmothers to practice the infant safe sleep recommendations.

## CHAPTER 4

### FINDINGS

This chapter presents the findings from the two focus groups with African American mothers and one African American grandmother. Following careful review of the focus groups transcripts, I identified common experiences and perceptions of the 11 focus group participants. Subsequently, six major themes emerged: (1) uncertainty that infant safe sleep recommendations will prevent SIDS, (2) the desire to ensure their infant is comfortable while sleeping, (3) the criteria for trusted sources of information, (4) difficulties quitting smoking during and after pregnancy (5) the ability to reduce risk when practicing behaviors that are not recommended and (6) skepticism about baby boxes.

#### **Sample Size and Demographics**

Eleven individuals participated in the focus groups. Six individuals attended the first focus group and five participants attended the second focus group. All participants identified as African American and consisted of ten mothers and one grandmother. The sample of parents ranged in age and experience. Some of the mothers were first-time mothers and some of them had previous children.

While the themes are reported as being distinct, there is considerable overlap among them. Thus, participants' responses to focus group questions often addressed more than one theme. In those cases, the focus group data are described where they appear to fit most logically.

*Theme 1: Uncertainty that infant safe sleep recommendations will prevent SIDS.* A recurrent theme during the focus groups was a sense amongst participants that following infant safe sleep recommendations won't necessarily prevent infant sleep-related deaths. This theme first emerged as we talked about participants' current infant sleep practices or intended practices as it relates to expectant mothers. After asking participants to go around the room and introduce themselves and state the age of their infant, I started both focus group conversations off by asking the participants to "tell us what happens when your baby get sleepy?" One participant from the first focus group noted their infant's behavior saying, "she gets whiny and sometimes she'll rub her eyes." I probed and asked where does the baby sleep and who puts the baby down to sleep and the participant stated that her infant sleeps in her crib. I followed up and asked her if this depends on who watches the baby and the mother stated that she is the only one who watches her. One participant at the second focus group stated that her infant son would start to "talk" a lot when he gets sleepy and that she places him down to sleep in his Pack 'n Play. I followed up and asked who puts him down to sleep and she replied that during the day his dad watches him, and she stated that he also puts him in the Pack 'n Play. A pregnant participant stated that she knows that she and her boyfriend sleep "wild," so she plans on having the baby sleep next to her bed in a bassinet. One participant noted that her baby sleeps in a baby bed and I followed up and asked if the baby's bed was in the same room or a different room and she replied the same room.

While several participants stated that they placed their infant to sleep in a crib or basinet, many participants also shared that they co-slept or planned to co-sleep with their infant. A pregnant participant shared that when she keeps her nieces and nephews they usually sleep with her. "Well, I have nieces and nephews and my nephew he started to cry a lot and he would sleep

in the bed because he would be at my house and I don't have a crib.” One of the expectant participants who has an eleven-year-old daughter also said that she will probably co-sleep with her infant daughter, but she noted that she does have a bassinet. She stated, “Even with my first daughter I kind of just had her sleeping with me on a boppy or something to prop her up.” Another participant stated that her son sleeps in his bassinet when he’s at home. However, she stated that when he’s with his grandmother he sometimes sleeps with her on the couch. A participant at the second focus group stated that her baby sleeps in the bed with her and that she is the only one who watches her baby.

The theme of uncertainty as it relates to infant safe sleep recommendations prevent infant sleep-related deaths reemerged during our discussions about SIDS. One of the participants stated that there isn’t a clear cause of SIDS. She put it, “they don't really honestly know what causes it. They just know that sometimes it happens.” There was a consensus among focus group participants that although laying the infant on their back to sleep is the safest position, that might not be enough to influence them to follow the recommendation. “Even though I know that laying her on her back is the most appropriate way. I’m not going to lie, I put it in God’s hands.” She went on to say that an elderly lady in her church told her to lay her daughter on her stomach.

*Theme 2: The desire to ensure their infant is comfortable while sleeping.* A central theme that emerged during both focus groups was the desire to ensure that their infant was comfortable while sleeping. Multiple participants noted that they prefer to hold their infants while they sleep. One participant stated, “I like the baby to sleep with me though anyways. I just like holding her and they are so precious when they sleep.” Another participant followed up and stated that if she puts her baby down she starts to cry. “If I put her in her bed after she sleep, and I put her in her bed she starts to cry.” Several participants stated that sometimes they’ll take the baby out of the bassinet or crib and put them in bed with them to stop them from crying.

I asked the grandmother participant if her daughter talked to her about how her daughter wanted her to place the baby to sleep.

Yeah, she said lay him on his back. But when she was little I laid her on her stomach because that’s how they had us doing it back in the 90s...but now that’s a no no, because the babies can’t really turn their heads and they spit up.

Another participant interjected and stated that “that’s the only way my baby will sleep though she don’t like sleeping on back.” She then went on to say, “She was holding her head up when she came out she was prepared for it.” She added that she wanted to put her infant on her back, “but she wasn’t falling asleep fast enough for me.” Another participant stated that she felt the stomach was the most comfortable for the baby. One of the participants interjected and stated, “my baby likes her side, if I lay her on her back she roll over to her side.”

When asked what images come to mind when you think about keeping your child or grandchild safe while he or she sleeps, one participant stated that she keeps blankets and pillows all around her daughter when she sleeps to protect her from scratches. Regarding keeping infants safe while they sleep another participant said, “I like just holding the baby. I know that’s spoiling

them and they gone end up being a bigger crybaby.... but I feel like that's the safest way." One participant said that one time her baby was choking on her back and that scared her. She said she rushed and put her baby on her side. Another participant said she doesn't use a crib bumper, but she wants to know how to protect her baby from getting stuck in the rails.

***Theme 3: The criteria for trusted sources of information.*** I asked the participants to read the NICHHD's *Safe Sleep for Your Baby* brochure. The brochure provides an overview of SIDS and consists of 13 infant safe sleep recommendations including placing the infant on their back to sleep at each sleep event, using a firm sleep surface, roomsharing but not bedsharing, not smoking, and breastfeeding. After reading the brochure, I asked participants if they felt the brochure was easy to understand and participants at both focus groups stated that they felt the brochure was easy to understand and that the information was useful. As one participant put it, "It's a standard that you can at least start off with."

When asked what makes it the most difficult for you and other caregivers you know to do the things you saw and read about in the brochure?" One focus group participant said it would be difficult to get the baby to sleep in her bassinet. "I let her sleep with me. I don't see what's the problem with that." I probed and asked if she had tried to place the baby to sleep in the bassinet and she stated that she had, but that the infant doesn't like it.

Multiple participants noted having children as an important characteristic of trusted sources. When asked when it comes to learning about safe sleep, who are you most likely to trust or listen to advice from? Some participants stated parents, mothers, grandmothers and doctors. I probed and asked about nurses and participants stated some nurses. One of the other participants at the first focus group then said, "it depends when it comes down to doctors and nurses it depends on if they have kids." She went on to say, "When I listen to advice from people I like to

listen to people who are experienced.... not somebody who done went to school an don't have experience.”

A participant at the second focus group talked about the importance of the relationship she has with her doctor for establishing trust.“ It depends on my relationship with my doctor and the baby’s doctor because I mean if they're more concerned and you know help me out a lot more versus just hey alright...just get you in and get you out.” She went on to say, “If you’re not taking the time to get to know my child, how can you give me information on my child, because every kid is different.” Another participant chimed in and stated that trusting her doctor depends on how they examine her baby and take the time to explain and show things to her.

When asked when it comes to learning about safe sleep, who are you most likely to trust or listen to advice from? Almost all participants stated their mother or grandmother. One participant stated that sometimes she will ask her doctor about advice that her mom gave her pertaining to caring for her infant. “You see like sometimes my mom will say something about my baby and I’ll go to the doctor about it and it don’t be nothing. So, I do prefer to listen to my doctor than my mama.” Another participant said she only likes to listen to the wise, older people. One participant interjected and sometimes they share myths. She then recalled a moment when an older lady told her to dip her baby to get her to go to sleep.

When asked where they would like to receive infant safe sleep messages, multiple participants noted the hospital. One participant stated that she had to watch a video about safe sleep before leaving the hospital. “You see my baby was in the NICU so before I could take my baby home I had to the Safe Sleep video...” Another participant stated that she was bored during her hospital stay and that receiving information on infant safe sleep would have been a good use of her time. The majority of participants at the first focus group stated that they would appreciate



a home visitor coming to share information about infant safe sleep. Participants stated that television was a viable choice for sharing messages. One participant stated that social media was a good option to reach younger caregivers. “Social media too, because I’m young and kids around my age, that’s all they do is be on social media. “Another participant stated that she would appreciate something that she can hang in the infant’s room so that other caregivers could also see the messages when placing the infant to sleep. Along similar lines, one participant said she would like a refrigerator magnet. One mother stated that she had downloaded the *Ovia Pregnancy* mobile app during her pregnancy that provided her with helpful information about her baby’s development.

Participants said that they felt the brochure was informative. I probed and asked what elements of the brochure stood out the most. One participant said, “pictures draw my attention.” Another participant, stated, “It’s the words.” All the participants noted that they were alerted when they saw the words, “risk”, infant death, SIDS, and safe.” “Anytime you see something say, ‘safe’ and you know it has to do with a baby you gone pay attention.”

***Theme 4: Difficulties quitting smoking during and after pregnancy.*** When asked what makes it most difficult for you and other caregivers you know to do the things you saw and read in the brochure, several of the participants mentioned quitting smoking. Another participant stated, “I know it’s not right, but smoking while you’re pregnant. I don’t do it anymore, but I did it at the beginning of the pregnancy and it was very hard for me to stop.” Another participant responded that she was told so many different things about smoking while pregnant by different people. I asked the group to share what guidance their doctor provided about smoking during their pregnancy and one participant replied, “He told me to slow down.”

In fact, one participant asked why mothers shouldn’t smoke during pregnancy. She went on to say she struggled with stopping smoking during her pregnancy, but she finally stopped because her child’s father was strongly against it. Later, another participant mentioned that she had stopped breastfeeding because she couldn’t stop smoking. A shared criticism of the brochure was that the brochure should provide more supporting information, such as why smoking during and after pregnancy is a risk factor for SIDS. As one focus group participant stated, “If they're going to give the reasons for a certain thing because it's like a little bit more informative as to why.”

***Theme 5: The ability to reduce risk when practices behaviors that are not***

***recommended.*** Another theme that arose during our focus group discussions was the ability to reduce risks for infant sleep-related deaths when practicing non-recommended behaviors. As we conversed about SIDS risk and protective factors, there was a sense among participants that when practicing behaviors that are not recommended, they could also mitigate risks by monitoring the infant.

If I do lay her on her stomach I check on her...I try to check on her like every five to ten minutes...every once in a while, I'll go in her room and check on her and make sure the little blanket...cause she loves putting stuff in her face. So, she'll snuggle the little blanket in her face and what not, so I have to just pull the blanket off of her nose and make sure she's breathing...I just check on her to make sure she's still breathing.

A participant at the first focus group stated, "Well in the day time like when I'm cleaning up and like washing bottles and stuff or even when I'm in the room I put her in the middle of my bed...not the top, not the bottom, just the dead center of my bed." The participant went on to say that she places the baby in the center of the bed to prevent the baby from rolling off the bed.

When I asked participants if they had ever heard about babies dying while they are asleep, three of the participants from the first focus group stated that they knew a baby who either died during their sleep or knew someone who had a baby who died who died in their sleep. One of the participants went on to say, "with my first son, I never heard of SIDS." But like these last two years that all I hear..." She also shared with the group that one of her friend's son died from SIDS in December 2018 when he was three weeks old. I followed up and asked what, if anything, do you think could be done to prevent this type of death? One participant said, "you

not supposed to lay them on their side or the stomach.” The grandmother participant interjected and said, “and no stuffed toys or pillows...nothing in the bed with them.”

A subtheme that emerged was this idea that infant safe sleep recommendations should not be one size fits all. One participant said she didn't feel that sleeping on the stomach was right for all babies. She indicated that the recommendation might be suitable for infants who can't lift their heads. She went on to say that the recommendations should say, “don't let them sleep on their stomach if they can't lift their head.” She also stated that her daughter sleeps on her stomach. “She sleeps good on her stomach. She sleeps wonderful and I love it...for a long time...four or five hours. I'm enjoying my sleep.”

***Theme 6: Skepticism about Baby Boxes.*** When asked about baby boxes, only one participant had heard of the baby boxes prior to the focus group. I probed and asked what have you heard? The participant stated that she had heard that some states provided the baby boxes if parents went to a class like this. There were mixed perspectives about how each group felt and responded to the baby boxes. When I asked to share their thoughts about baby boxes, participants at both focus groups seemed to have doubts regarding the baby boxes. “I mean yeah, but...I don't know. It's not see-through.” A common view amongst participants was that the thought of placing their infant in a cardboard box was uncomfortable. As one participant at the second focus group put it, “the fact that it is a cardboard box makes it off-putting” Another participant had similar sentiments. “The thing that kind of threw me off was the fact that it's a cardboard box.”

During the first focus group, one of the participants stated that travel bassinets were a better option for parents. “You better off with the travel bassinet. Like the one Grady gave us...it's very small like it folds out like that and it's very light.” Multiple participants noted that

the box would be a suitable option for someone who didn't have a bassinet or crib. One participant said this is an option for a person who didn't have a travel bassinet, but she said she felt most women would be more likely placing their baby to sleep on a bed. Although, most participants at both focus groups noted that they felt the box was safe, one of the participants at the second focus group felt the baby would be too "high" in the baby box.

### **Summary of Findings**

In this chapter, I presented the findings of the study. These findings are based primarily on the analysis of focus group transcripts and are supported by reviewed documents and observations during each focus group. Findings were discussed in six sections that correspond with the major themes that emerged from the data. Chapter V discusses the reoccurring themes from the focus groups and recommends future practice and research.

## CHAPTER 5

### DISCUSSION

#### **Summary**

The intent of this study was to explore perceptions of infant safe sleep interventions among low-income African-American mothers and grandmothers to develop recommendations for the development of a culturally tailored infant safe sleep intervention to increase adherence to evidence-based infant safe sleep recommendations. Research was conducted through two focus groups with eleven Healthy Start participants in the metro-Atlanta area. This chapter reviews, analyzes, and discusses the findings of this study. This chapter also outlines the implications of the findings for developing culturally tailored infant safe sleep interventions for African American mothers and grandmothers. This chapter concludes with suggestions for further research. Through qualitative methods, this study set out with the following aims:

1. Describe African American mothers and grandmothers' beliefs and perceptions of infant's risk susceptibility for an infant sleep-related death.
2. Describe African American mothers and grandmothers' attitudes toward established infant safe sleep recommendations.
3. Describe African American mothers and grandmothers' perception of baby boxes for use of an infant sleep environment.

## **Prevailing Themes**

Six themes emerged during the discussions: (1) uncertainty that infant safe sleep recommendations will prevent SIDS, (2) the desire to ensure their infant is comfortable while sleeping, (3) the criteria for trusted sources of information, (4) difficulties quitting smoking during and after pregnancy (5) the ability to reduce risk when practicing behaviors that are not recommended and (6) skepticism about baby boxes. Themes were consistent across both focus groups.

### **Theme 1: Uncertainty that infant safe sleep recommendations will prevent SIDS.**

The findings regarding the uncertainty among participants that infant safe sleep recommendations will reduce the risk of SIDS are in line with the findings of several previous works (Colson, McCabe et al. 2005, Moon, Oden et al. 2010, Hackett and Simons 2013). Most of the mothers were aware of SIDS and were familiar with infant safe sleep recommendations; though, participants were less aware of the rationale for the recommendations, particularly recommendations related to smoking and choking. A compelling body of evidence indicates that African American mothers are knowledgeable of, however, do not practice infant safe sleep recommendations (Taiwo I Ajao, Oden, Joyner, & Moon, 2011; Gaydos et al., 2015; Herman et al., 2015; Joyner, Oden, Ajao, & Moon, 2010). Previous research findings suggest that SIDS myths may be responsible for some mothers' decisions to not follow infant safe sleep recommendations despite being knowledgeable of the dangers of certain sleep practices. In their study about infant safe sleep beliefs among African American and American Indian families, Herman, Adkins, & Moon (2015) found that some mothers believe SIDS is a disease or syndrome and therefore, one can't protect their infant from SIDS. As mentioned in Chapter 2, previous studies demonstrate that many parents do not believe that their behavior except for

vigilance can affect SIDS risk because they view SIDS as a random act of God (Fern R Hauck, Tanabe, & Moon, 2011). Three participants shared that they knew a relative or friend who had a personal experience with SIDS. However, this did not seem to deter participants from practicing behaviors associated with increased infant sleep-related deaths (e.g., bedsharing with the infant, placing the infant in the prone sleep position, putting blankets and pillows in the infant sleep environment). In fact, one of the mothers in this study said that she knows the back is the safest sleep position for her baby, but she chooses to put it in God's hands. We will discuss this finding in more detail when we talk about trusted sources. Moreover, a couple of the participants did not believe their infant was at risk for an infant sleep related death because they were currently practicing behaviors that had been associated with an increased risk of infant sleep-related deaths and had not had a negative experience. An example of this is when a mother noted that she has been bedsharing with her infant daughter since birth and she doesn't see a problem with it.

**Theme 2: The desire to ensure their infant is comfortable while sleeping.** A recurrent theme in the focus groups was the desire among mothers to ensure their infants' comfort during sleep. There have been several studies in the literature reporting that mothers make decisions about their infants' sleep locations and positions based on their perceptions of their infants' physical and emotional comfort and perceptions of what was safe, effective, and convenient in meeting the needs of their infants while also meeting their own need for rest (Ajao et al., 2011; Canter, Rao, Patrick, Alpan, & Altman, 2015; Colson et al., 2005; Joyner et al., 2010). The following 3 sub-themes emerged as we discussed infant comfort: (1) infant sleep location; (2) infant sleep position; and (3) items in sleep environment.

***Infant sleep location.*** Most of the participants stated that their infant had a dedicated sleep location (e.g., crib or bassinet). However, several participants shared that they bedshare



with their infants because their infant did not like sleeping their crib or bassinet. Results from previous studies indicate that parents choose to bed share for several reasons, including convenience of feeding, space considerations, safety concerns, cultural traditions, and enhanced sleep of the infant (Fern R. Hauck, Thompson, Tanabe, Moon, & Vennemann, 2011; Keene Woods et al., 2015; Lau and Hall 2016). One participant noted that when she is at home her son sleeps in his bassinet, but when he visits his grandmother he often sleeps on the sofa. This revelation is alarming because Black infants who die from SIDS are more than 1.5 times as likely to have been placed on a sleep surface other than a crib, such as an adult bed, sofa, or waterbed (Fern R Hauck et al., 2011). In their study, Gaydos et al. (2016) examined the differences between grandmothers' behavior in their own homes compared to the home of the parent, along with whether safe sleep practices were associated with beliefs in common myths about sleep safety. The results of this study support the idea that infant safe sleep interventions should emphasize the importance of placing infants to sleep in a designated sleep environment during all sleep events, including when visiting other homes.

***Infant sleep position.*** Turning now to infant sleep position, a common view among focus group participants was that infants fell asleep more quickly and slept for longer durations of time when placed on their stomachs. For instance, one of the parents in the study attributed her decision to place the infant in the prone sleep position to the fact that her daughter slept longer on her stomach which allowed her to also get rest. This finding supports Caraballo et al. (2016) findings' which showed that mothers are more likely to bedshare to improve their own sleep.

***Items in Sleep Environment.*** When asked what images come to mind when keeping your infant safe during sleep, one participant stated that she likes to have lots of pillows and blankets

around her daughter when she sleeps to protect her from scratches. Several studies have revealed that some parents perceive that the infant will sleep more comfortably if placed on a soft surface or that the soft bedding will prevent injury (e.g., from bumping into crib railings or falling off the bed or sofa) (Ajao et al., 2011; Hauck et al., 2011). Further, Ajao et al. (2011) found that mothers were more likely to use soft bedding to enhance infant comfort despite recommendations to place infants in empty cribs. One participant asked how she should prevent her infant from getting stuck in the crib rails if she doesn't use bumper pads. This finding suggests that infant safe sleep interventions should also provide education on how to protect infant from entrapment.

**Theme 3: The criteria for trusted sources of information.** As mentioned in Chapter 2 of this dissertation, previous studies have shown that there is a correlation between receiving information about infant sleep and infant care practices and trusting that information from said physician for parents to adhere to the guidance. Trust can be understood as individuals seeing one another as competent, responsible, caring, tactful and ethical (Jones, Carson et al. 2012). Participants noted having children as an important prerequisite for trusting their healthcare provider's guidance related to infant sleep practices. This finding is consistent with findings of past studies by Caraballo et al. (2016) in which several mothers reported they were more likely to trust people with children of their own, whether medical provider, friend, or family member. Almost all participants stated that they listen to their mom or grandmother for advice on infant safe sleep. As mentioned earlier, one of the participants noted that an older woman at her church told her to place her infant on her stomach to sleep. Data from previous research findings suggest that older female caregivers, especially grandmothers, are key sources of influence on the infant rearing decisions, particularly sleeping decisions (Brenner, Simons-Morton, Bhaskar, & et al., 1998; Eve R. Colson et al., 2006; Oden, Joyner, Ajao, & Moon, 2010). Further, in a recent study

of key healthcare professionals, Thornhill-Scott, Redmond, Dong, and Ablah (2016) reported that most respondents cited cultural beliefs and practices as impediments to parents following infant safe sleep recommendations. Findings from previous research posit that parents may reject advice against bed sharing from professionals when it differs from their own beliefs (Ball & Volpe (2013); Austin, Nashban, Doering, & Davies, 2017).

In the present study, participants also cited their relationship with their doctor as an important factor for establishing trust. Previous research findings demonstrate that people are more likely to heed advice from sources they trust (Austin et al., 2017; DiMatteo, 2004; Hackett & Simons, 2013). Furthermore, Colson, Levenson et al. (2006) found that mothers who trusted the guidance provided by their doctor or a nurse about infant sleeping position were more likely to place their infants in the supine position. There are similarities between the attitudes expressed by the participants in this study and those described by Hwang et al. (2016). Hwang et. al (2016) reported that 80 % of mothers trusted doctors while only 35 % trusted nurses for advice on infant sleep position. One mother stated that she only listens to nurses some of the time. Colson, Levenson et al. (2006) found that mothers who trusted the guidance provided by their doctor or a nurse about infant sleeping position were more likely to place their infants in the supine position. Similarly, Coleman (2009) found that when African American mothers with infants between the age of 0 to 6 months encounter nurses with a positive and supportive demeanor they are more likely to adhere to nurse recommendations.

Some parents cited home visiting programs as being the preferred method for receiving information related to infant safe sleep. Participants also noted that they would appreciate a poster or magnet that reinforces infant safe sleep messages. Others felt that showing educational videos about SIDS at the hospital prior to discharge and placing infant safe sleep messages on

social media would be good channels for sharing messages about infant safe sleep. In a previous study, mothers who reported observing recommended sleep practices while in the hospital was significantly higher among those who viewed the video (Canter, Rao et al. 2015). Participants across both focus groups noted that the brochure was easy to read and that it contained helpful information. Nonetheless, multiple participants expressed frustrations that the infant safe sleep brochure did not explain the rationale behind infant safe sleep recommendations. Mothers also expressed that the brochure did not address developmental differences among infants, such as being able to lift their heads. In fact, one participant stated that the recommendations should include qualifying statements, such as “place infant on their back if they cannot turn their head.” This finding matches those observed in earlier studies, in which mothers thought infant safe sleep guidelines should include alternative strategies to keep the infant safe while promoting sleep (Herman, Adkins, & Moon, 2015).

**Theme 4: Difficulties quitting smoking during and after pregnancy.** Several mothers reported difficulties quitting smoking while pregnant and one mother who stopped smoking during her pregnancy said she had to quit breastfeeding because she resumed smoking shortly after the birth of her daughter. Findings from previous research studies demonstrate that infants born to mothers who smoked during pregnancy are three times more likely to die of SIDS than those born to mothers who did not smoke during pregnancy (Tong, England, & Glantz, 2005; Ball & Volpe, 2013; Liebrechts-Akkerman et al., 2011; Wisborg, Kesmodel, Henriksen, Olsen, & Secher, 2000). One participant noted that she stopped smoking due to pressure from her child’s father. This revelation supports the notion that fathers are powerful influences on infant sleep decisions.

**Theme 5: Ability to reduce risk when practicing behaviors that are not recommended.** One of the more significant findings to emerge from this study is that many mothers believe they can mitigate the risk of SIDS when practicing behaviors associated with increased infant sleep-related deaths, such as bedsharing or prone sleeping. For example, one participant noted that she frequently checks on her infant while she's sleeping on her stomach. The mother went on to say that she constantly pulls the blankets from over her daughter's face when she's sleeping. One mother noted that she places her infant daughter in the middle of her bed during the day while she does chores and errands around the house. This finding mirrors those of Lau (2016) and suggests that mothers view sleep events during the day as less risky for SIDS than nighttime sleep.

**Theme 6: Skepticism about baby boxes.** Several infant safe sleep interventions have explored the effectiveness of providing participants with resources (e.g., cribs, onesies, wearable blankets) to support following established infant safe sleep recommendations (Ahlers-Schmidt et al., 2014; Carlins & Collins, 2007; Hauck et al., 2015; Salm Ward et al., 2018). Multiple participants stated that they received travel bassinets from Grady Hospital and Atlanta Medical Hospital, hospitals in the Atlanta metropolitan area. In 2016, the GDPH launched the Georgia Safe to Sleep Hospital Initiative as part of a statewide multi-pronged safe sleep campaign (Miller et al., 2018). The campaign provided caregivers with infant safe sleep education and travel bassinets for Medicaid and uninsured patients (Walcott et al., 2017). All 77 birthing hospitals in Georgia participated in the *Safe to Sleep* Campaign. Similarly, some states including New Jersey, Ohio, and Alabama have started providing boxes to mothers as an alternative sleep environment for infants. More recently, Ahlerts-Schmidt et al. (2017) investigated parental attitudes towards baby boxes in a qualitative study. She reported that participants expressed concerns about the

box's safety, including hazards (such as pets or other children) getting into the box, and the potential for people to kick or trip over the box, especially at night.

Most participants didn't feel that the baby box was suitable for their infants but expressed that the baby box might be a viable option for families with limited resources. This finding supports the conclusion drawn from Ahlerts-Schmidt et al. (2017) qualitative study in which some interviewees remarked that the baby box was only appropriate for people with a lower SES.

## **Implications**

The following recommendations are divided into two sections. The first section presents a set of recommendations for intervention developers. The second section offers a set of recommendations providing suggestions for future researchers in exceeding the scope of this study. Recommendations are based on the results of this study.

## **Recommendations for Developing A Culturally Tailored Infant Safe Sleep Intervention**

- 1) Additional information needs to be provided to support the rationale for infant safe sleep recommendations. This study can be used to confirm the need to provide evidence supporting the infant safe sleep recommendations, such as avoiding smoking during and after pregnancy.
- 2) Target infant safe sleep interventions to include grandmothers and other caregivers. Address outdated and inadequate information that might be shared by grandmothers and other older caregivers. Interventions need to address the reasons behind the change in infant safe sleep recommendations over the years.
- 3) Address concerns such as protecting infant from risk of head or leg entrapment between crib rails when sleeping in a crib without bumper pads. Education needs to be shared on

the fact that new crib standards require crib slat spacing to be  $<2\text{-}3/8$  inches removing the need for crib bumpers.

- 4) Provide free cribs or bassinets to families or provide participants with information on where they can receive free/reduced cost sleep environments. Multiple participants noted that they used or intended to use travel bassinets provided by their birthing hospital as their infant's sleep environment.
- 5) Provide parents with educational reinforcements to take home such as posters, magnets or door hangers that demonstrate infant safe sleep messaging and photography.
- 6) Focus on strangulation and suffocation. Infant safe sleep recommendations should frame messages in terms of preventing behaviors that increase suffocation and strangulation such as placing items in the crib or bedsharing.
- 7) Offer additional ways to soothe infant who cries when placed on their back or when placed in a separate sleep location.

### **Recommendations for Policy or Practice**

The results from this study can be used to design and provide a much-needed infant safe sleep intervention for African American mothers and grandmothers. As demonstrated in this study and other studies, older female caregivers, especially grandmothers, are key sources of influence on the behavior of mothers, and the proportion of children being reared by their grandparents is increasing. It is therefore also important to develop interventions that target this influential group to ensure they are aware of and adherent to the recently changed guidelines.

Additional information needs to be provided to establish the rationale for each recommendation. Several participants noted that they wanted to know why this guidance was issued and how these recommendations protect an infant from SIDS. Therefore, there future interventions need to explain how these recommendations protect the infant and how certain behaviors increase an infant's risk of sleep related deaths. These results also demonstrated that

there is still a need to dispel myths about SIDS. Thus, there needs to be more focus on tangible issues such as asphyxiation and suffocation. Trust in healthcare professionals is associated with increased adherence to health care recommendations. Multi-pronged infant safe sleep interventions should also focus on health care professionals. Some mothers may not intend on bedsharing prior to bringing the baby home. For this reason, infant safe sleep education should be reinforced at the infant's first well baby visit or during home visits.

### **Limitations**

The findings of this study are limited by several factors. First, originally this study sought to include African American mothers and grandmothers; however, after several attempts to reach grandmothers through various organizations including health clinics and kinship care programs, we were only able to recruit one grandmother to the study. Secondly, the research team did not distribute exit surveys during the first focus group. Thirdly, mothers were a part of the Healthy Start program, so they receive additional support and information about caretaking topics, including infant safe sleep through their participating in the program.

### **Conclusions**

The voices of these participants afford a unique insight of how they perceive infant safe sleep recommendations and suggests that culturally tailored infant safe sleep interventions should include grandmothers and provide supporting evidence to increase adherence of infant safe sleep recommendations. Future studies should continue to explore the reasons African American mothers and grandmothers do not comply with infant safe sleep recommendations. Further, researchers need to evaluate whether culturally tailored interventions can adequately address these barriers.



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## APPENDIX A

### FOCUS GROUP DISCUSSION GUIDE

## Focus Group Discussion Guide

### Introduction

Let's start by going around the room and introducing ourselves. As you do, please tell us how many children/grandchildren you care for and their ages.

### Current Attitudes/Practices

- Thank you for sharing that! Today, we would like to learn more about how you care for your children/grandchildren under the age of one. Specifically, we are interested in learning more about how you get your infant child/grandchild to fall asleep.
- To start, could you please tell us what happens when the baby gets sleepy?
  - Where does the baby sleep?
  - Who puts baby down to sleep?
  - Does any of this depend on who is caring for baby, or where baby is (at home vs. another setting)?
- What do you do when it is difficult to get baby to fall asleep?
  - What works well?
  - What hasn't worked so well?
- **For grandparents:** Has your daughter (or the child's mother) talked to you about how your baby should be placed to sleep?
- Have you ever heard about babies dying while they are asleep?
  - What have you heard about this?
  - What words do you and the people you know use to talk about these kinds of deaths?
  - What do you and the people you know call these deaths?
  - What do you think causes these deaths?
  - What, if anything, do you think could be done to prevent this type of death?
- When you think about keeping your child/grandchild safe while he or she sleeps, what images come to mind?
- How do you keep your child/grandchild safe while he or she sleeps?

### Barriers to Safe Sleep

Next, we are going to ask you to read a brochure with information about keeping babies safe while they sleep. We would like your feedback on these materials so that new materials can be



developed that better meet the needs of African American parents and caregivers. We understand that caring for a new baby is a lot of work and that it is exhausting. I can imagine that it might be difficult to follow all of these safe sleep recommendations all of the time.

- What makes it the most difficult for you and other caregivers you know to do the things you saw and read about in the brochure?
- Was the information presented in a clear and understandable manner? (What do you think about it?)
- Is there anything you would change about the information? What would you keep the same?
- Do you think this information in the brochures are useful/applicable to you? Why or why not?
- What makes it difficult to get baby to sleep in a crib, bassinet or pack and play?
- How well do these materials address your concerns as a parent/grandparent/caregiver?
- What other concerns do you have about keeping your child/grandchild safe while they sleep?
- What do you think you would need to make it easier to follow these messages?
  - Are there resources that you have tried to access, but were not able to? (If so, which ones?)

### **Baby Boxes**

- Have you heard of baby boxes?
  - What have you heard?
  - What are your thoughts about baby boxes?
- Would you feel comfortable placing your child/grandchild to sleep in a baby box?

### **Trusted Sources/Preferred Channels**

- In the future, how would you like to learn more about keeping your child/grandchild safe while he/she sleeps?
- When it comes to learning about safe sleep, who are you most likely to trust or listen to advice from?
  - Why are you most likely to trust or listen to advice from those sources?
  - Why are you least likely to trust or listen to advice from other sources?
- Where would you like to see these messages or hear more about safe sleep (Facebook, email, text, TV, printed materials, from a healthcare provider or home visitor, etc.)?
- If you were going to keep information about infant safe sleep in your home (or near where baby sleeps) as a reminder, what method would you like for information to be shared in (door hanger, magnet, flyer, poster, etc.)?
- When you receive informational materials, what aspects of those materials are most important to you?
  - ...the images being used?

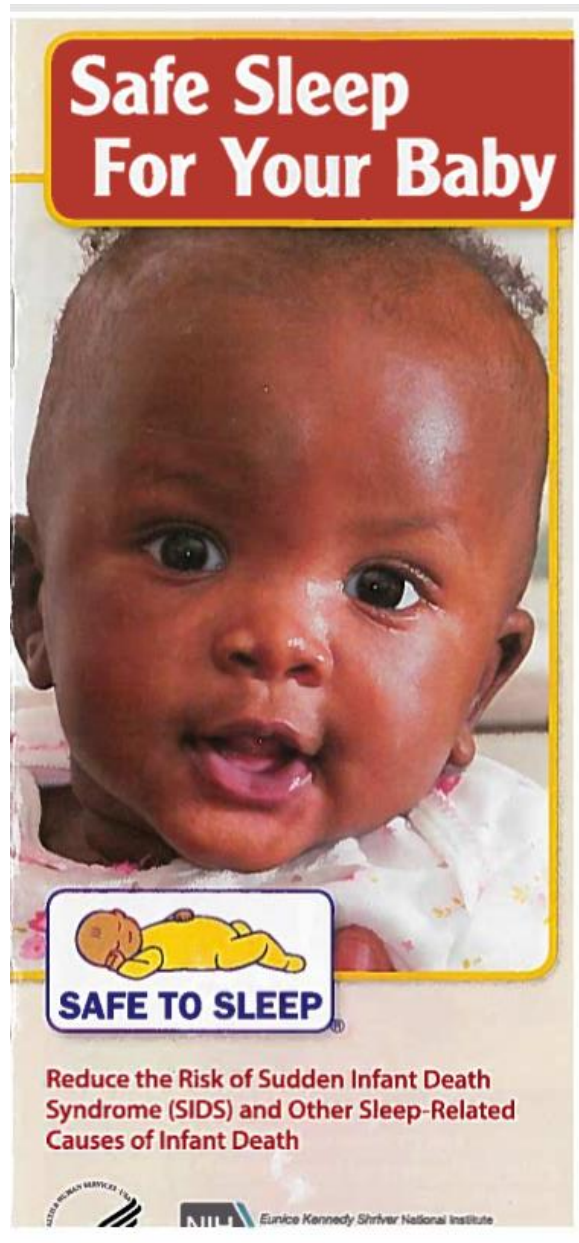
- ...the families and babies shown? (specifically ask about race, age, and gender of caregivers shown)
- ...the words that are used?
- ...the method used to convey the message (Facebook vs. text vs. email vs. video vs. brochure vs. other)?

**Conclusion**

- What else would you like to tell us about keeping your child/grandchild safe while he or she sleeps?


APPENDIX B

INFANT SAFE SLEEP BROCHURE



## APPENDIX C

### RECRUITMENT FLYER



**Are you an African American grandmother, mother or caregiver of a baby less than 1-year-old?**

**We want to hear from you!**

We want to hear your thoughts on infant sleep, infant safe sleep interventions, and infant safe sleep recommendations.

We will be conducting focus groups. The focus group should last no longer than 90 minutes. Answers and comments will be anonymous.

As a thank you for your time and participation, you will receive a \$50 gift card and free dinner. If you recommend another individual who is eligible to participate in the study, you will receive an additional \$15 gift card, so in total you can earn \$65!

If you would like to participate in the individual interview, please email **Marcie Dumolga** at [marcie08@uga.edu](mailto:marcie08@uga.edu) or call 470-809-3316. For questions or concerns about the research study, please contact Principal Investigator, Dr. Jessica Muilenburg at [jlm@uga.edu](mailto:jlm@uga.edu) or 706-542-4365.

## APPENDIX D

### IPA FCOS GROUP ANALYSIS PROTOCOL

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**Table 1**

Summary of protocol for using IPA with focus group data

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**1. Objects of Concern and Experiential Claims**

- a. Pick out experiential claims and concerns as they appear in the transcript.
- b. Summarise these, and sort into emergent patterns.

**2. Positionality**

- a. Explore the role played by facilitators, keeping track of questions, permissions, encouragements, redirections, etc. (What is their perspective, stance, position?)
- b. Explore the function of statements made by respondents. (What is their perspective, stance?)

**3. Roles & Relationships**

- a. Examine references to other people: What roles and relationships are described? What sorts of meanings and expectations are attributed to these relationships?
- b. What are understood to be the consequences of these?

**4. Organisations & Systems**

- a. Examine references to organisations and systems: How are they described? What sorts of meanings and expectations are attributed to these?
- b. What are understood to be the consequences of these?

**5. Stories**

Examine the stories told by participants: look at the structure; genre; imagery and tone. What does each story achieve? How do participants support or impede each other to share their experiences? What temporal referents exist?

**6. Language**

Throughout stages 1–5, monitor language use, paying particular attention to use of metaphor, euphemism, idiom, etc. Consider:

*a. Patterns*

Repetition, jargon, stand-out words and phrases, turn-taking, prompting – are these identified in individuals or the whole group?

*b. Context*

Impact on language used; descriptions of feelings/emotive language; jargon and explanation of technical terms; impact of facilitator.

*c. Function*

How/why is certain language being used? (e.g. to emphasise/back-up a point, to shock, to provoke dis/agreement, to amuse/lighten the tone?)

**7. Adaptation of Emergent Themes**

Return to the emergent themes from step 1b. and adapt them according to the work done subsequently. Answering the following questions will help:

- a. What experiences are being shared?
  - b. What are individuals doing by sharing their experiences?
  - c. How are they making those things meaningful to one another?
  - d. What are they doing as a group?
  - e. What are the consensus issues?
  - f. Where is there conflict? How is this being managed/resolved?
- 

*(Continued)*

## APPENDIX E

### CONSENT FORM

#### UNIVERSITY OF GEORGIA CONSENT FORM Infant Safe Sleep Focus Group

##### **Researcher's Statement**

I am asking you to take part in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. This form is designed to give you the information about the study, so you can decide whether to be in the study or not. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." A copy of this form will be given to you.

**Principal Investigator:** *Jessica Muilenburg, PhD*  
[jlm@uga.edu](mailto:jlm@uga.edu)

**Co-Investigator:** *Marcie McClellan Dumolga, MA*  
*Health Promotion and Behavior*  
[Marcie08@uga.edu](mailto:Marcie08@uga.edu)

##### **Purpose of the Study**

You are invited to participate in a survey on infant safe sleep recommendations. The purpose of this focus group is to learn about attitudes, beliefs and feelings about infant safe sleep, including infant safe sleep recommendations and infant safe sleep interventions. This information will be used to adapt an infant safe sleep intervention for African American caregivers.

##### **Study Procedures**

If you agree to participate, you will be asked to share your thoughts and feelings on infant safe sleep, including recommendations, infant safe sleep interventions and materials. The focus group discussion will take about 90 minutes of your time.

##### **Risks and discomforts**

There are no foreseeable risks involved in participating in this study.

##### **Benefits**

You will receive no direct benefits from participating in this research study. However, your responses may help us learn more about African American caregivers learn about infant safe sleep recommendations.

**Incentives for participation**

You will receive a \$50 gift card to Target or Walmart and free lunch/dinner in appreciation for your participation. If you refer an individual to the study who is eligible to participate and completes an interview, you will receive an additional \$15 gift card.

**Audio/Video Recording**

The focus groups will be audio-taped, and the audio-tapes transcribed, to ensure accurate reporting of the information that you provide. No one’s name will be asked or revealed during the focus groups.

By initialing here, you agree to allow us to audio record you during this focus group. \_\_\_\_\_

**Privacy/Confidentiality**

If you choose to participate, you will not be asked your name at the interview. You will not need to use your name in the focus groups. If by chance, you use your name during the interview, the transcriber will be instructed to delete all names from the transcription.

While every effort will be made to keep confidential all the information you complete and share, it cannot be absolutely guaranteed. Individuals from the University of Georgia’s Institutional Review Board (a committee that reviews and approves research studies), and Federal regulatory agencies may look at records related to this study for quality improvement and regulatory functions.

There will however be no names attached to the tapes or transcriptions, and there will be no identifying information or names used in any written reports or publications which result from this focus groups. Your participation in this evaluation will be strictly confidential.

**Taking part is voluntary**

Your involvement in the study is voluntary, and you may choose not to participate or to stop at any time without penalty or loss of benefits to which you are otherwise entitled.

**If you have questions**

If you have any questions about this research project, please feel free to call me, Marcie McClellan Dumolga at 470-809-3316 or send an e-mail to [marcie08@uga.edu](mailto:marcie08@uga.edu). You may also contact the Principal Investigator, Dr. Jessica Muilenburg at [jlm@uga.edu](mailto:jlm@uga.edu) or 706-542-4365. Questions or concerns about your rights as a research participant should be directed to The Chairperson, University of Georgia Institutional Review Board; telephone (706) 542-3199; email address [irb@uga.edu](mailto:irb@uga.edu).

**Research Subject’s Consent to Participate in Research:**

To voluntarily agree to take part in this study, you must sign on the line below. Your signature below indicates that you have read or had read to you this entire consent form and have had all of your questions answered.

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Please sign both copies, keep one and return one to the researcher.