Caregiver-infant bed-sharing experiences

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Dedication

This dissertation is dedicated to my daughters, Ella and Marley. You are the reason for my fascination with the inexplicable love between parent and child.

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ABSTRACT

Caregiver-infant bed-sharing has become increasingly controversial in Western industrialized countries over the past few decades. In these countries, public health authorities recommend against all infant bed-sharing given that some infants die while sharing a bed with their caregiver. However, anthropologists have demonstrated that caregivers and infants likely shared sleep surfaces for thousands of years, yielding an infant who has evolved to expect close human contact during sleep. In many countries, infant-caregiver bed-sharing is practiced widely without any increase in infant death rates or recommendations against the practice. It is important to examine bed-sharing in various contexts to understand the problem fully.

This manuscript is divided into three parts, each with a focus on infant bed-sharing, and builds toward the results of a study of caregiver-infant experiences of bed-sharing in Southern and South-Central Appalachia. Part I consists of a nursing perspective on infant bed-sharing using multidisciplinary theory integration. Part II presents the results of a systematic qualitative meta-synthesis on infant-caregiving experiences. Part III contains the results of a narrative analysis of caregiver-infant bed-sharing experiences in Southern and South-Central Appalachia.

This manuscript provides a wholistic overview of the infant-bed-sharing problem today with implications for nursing practice, research, and policy. This is a complex issue with wide-reaching implications for infant safety, development, and caregiver decision-making.

TABLE OF CONTENTS

INTRODUCTION 1

Background 2
Problem statement and purpose of this manuscript 12
Research questions 14
Philosophical perspective 15
Assumptions 17
Limitations 18
Delimitations 19
Significance of the study in Part III 19
References 21

PART I: A NURSING PERSPECTIVE ON INFANT BED-SHARING USING MULTIDISCIPLINARY THEORY INTEGRATION 30

Abstract 31
Introduction 32
The triple risk model of bed-sharing: Tenets, assumptions, and paradigm 33
Evolutionary theories of bed-sharing: Tenets, assumptions, and paradigm 36
Predictions made by the triple risk model of bed-sharing 38
Predictions made by evolutionary theory 40
Analyzing bed-sharing using theory integration 43
Implications for research and practice 44
Conclusion 45
References 46

PART II: A SYSTEMATIC QUALITATIVE META-SYNTHESIS OF CAREGIVER-INFANT BED-SHARING EXPERIENCES 53

Abstract 54
Introduction 56
Background 56
The review 58
Results 60

Discussion 68
Conclusion 71
References 74

PART III: A NARRATIVE ANALYSIS OF APPALACHIAN CAREGIVER EXPERIENCES BED-SHARING WITH THEIR INFANT 82

Abstract 83
Introduction 84
Background 85
Methods 86
Results 90
Discussion 121
Conclusion 126
References 128

CONCLUSION 133

Implications for research 133
Implications for practice 135
Implications for policy 138
Conclusion 146
References 147

APPENDICES 154
VITA 192

INTRODUCTION

Sudden Infant Death Syndrome (SIDS) is the number one cause of death among infants from 1–12 months and is defined as "the sudden death of an infant less than 1 year of age that cannot be explained after a thorough investigation is conducted, including a complete autopsy, examination of the death scene, and a review of the clinical history" (Centers for Disease Control & Prevention [CDC], 2019). In 2016, there were 3,607 cases of Sudden Unexpected Death in Infancy (SUDI) in the United States (U.S.), with 1,500 of these classified as SIDS, 1,200 classified as unknown, and 900 classified as accidental suffocation and strangulation in bed (CDC, 2019). In 2016, the American Academy of Pediatrics (AAP) updated safe sleep recommendations to include advice on ways to decrease bed-sharing risks while acknowledging the frequency of inadvertent bed-sharing. While these new recommendations include a short discussion about factors that increase risk during bed-sharing, the focus is still on complete avoidance (AAP Task Force on SIDS, 2016). Despite this focus, infant sleep-related deaths have not significantly dropped since the recommendations to place infants supine to sleep in the 1990s (Blair, Sidebotham, Berry, et al., 2006; CDC, 2019).

The U.S. has the highest rate of SUID and SIDS of all industrialized countries and there are large racial and socioeconomic disparities (Bartick & Tomori, 2019). The highest rates of SUID are seen in U.S. African American/Black and American Indian/Alaskan Native populations, and in Southern Appalachian counties (Singh et al., 2017). Besides bed-sharing, other identified risks include the same factors seen with other social determinants of adverse health effects like smoke exposure and abuse of alcohol and/or drugs (Bartick & Tomori, 2019). Studies have not consistently shown that bed-sharing is inherently risky in the absence of these major risk factors (Blair, Sidebotham, Pease, et al., 2014). In addition, widespread

recommendations against bed-sharing may lead to negative psychosocial and neurobiological consequences for infants and caregivers due to caregiver-neonatal separation during sleep (Hostinar et al., 2014). Nuanced views of bed-sharing that consider the sociocultural context of the underlying issues are imperative to decrease infant sleep-related death further while also promoting the optimal health of infants and their caregivers.

There are many experts who believe bed-sharing should be considered the normal context for infant sleep (McKenna & Gettler, 2017). However, studies also have shown a significant relationship between infant sleep-related deaths and bed-sharing in modern industrialized contexts (Carpenter et al., 2013). Anthropologists present evidence that infants evolved to expect close contact with their mothers and frequent breastfeeding throughout the night (Narvaez et al., 2013). Studies have shown many benefits to mother-infant bed-sharing, including physiologic synchrony, prolonged breastfeeding, enhanced attachment, and neuroendocrine regulation (Marinelli et al., 2019). While several large case-control studies have established risk factors for infant sleep-related death, these studies rarely consider the true prevalence of infant bed-sharing that occurs in the population (Blair, Sidebotham, Pease, et al., 2014; Carpenter et al., 2013). In some cultures with high bed-sharing rates, infant sleep-related deaths are rare (Bartick & Tomori, 2019). Thus, studies suggest that it is the context within which families bed-share that produces risk. In fact, most infant bed-sharing deaths now occur among marginalized groups within wealthy countries, leading researchers to call for a re-examination of this issue through the lens of marginalization (Bartick & Tomori, 2019).

Background

Caregivers admit they continue to share a bed with their baby despite strong recommendations about the risks, citing reasons like instinct, need for sleep, and frequent

breastfeeding (Culver, 2008; Joyner et al., 2010). In collective cultures, bed-sharing tends to be more common than in individualistic cultures like the U.S. (Mindell et al., 2010). Some speculate that enculturation about interdependence begins with the sleep environment. Other studies show that bed-sharing infants display more secure attachment and greater independence as they get older (Mileva-Seitz et al., 2016). Breastfeeding advocates tend to support bed-sharing and bed-sharing has been strongly linked with more frequent breastfeeding and delayed weaning (Ball, 2007). Anthropologists believe that in hunter-gatherer cultures, bed-sharing was near universal, which has led many scholars to consider bed-sharing an "evolved developmental niche" for human infants (Narvaez et al., 2013; Thoman, 2006). If bed-sharing constitutes the "expected" environment for human infant sleep, it is important to outline why there would be any association with infant death.

Risk factors for infant bed-sharing death

A review of factors increasing the risk of infant death while bed-sharing provides a rationale for why bed-sharing is so highly contested in some countries. For this review, articles were located using CINAHL, PubMed, and Scopus using variations of the keywords co-sleeping, bed-sharing, SIDS, SUDI, death, asphyxia, and suffocation. The search was limited to English, peer-reviewed articles published from 2009 to January 2020. Original research with a primary focus on risk factors associated with infant (i.e., 0–12 months of age) bed-sharing risks were included. For quantitative analyses, only population studies examining bed-sharing risks were included. All qualitative articles from 2009 to January 2020 examining infant risk while bed-sharing were included. In total, 13 studies were included in the final review, including one meta-analysis. The major risks identified in this review included exposure to cigarette smoke, caregiver alcohol and/or drug impairment, non-supine positioning, and unsafe sleep spaces (e.g.,

sofa, soft bedding). A literature matrix is included in Table A.1.

Smoke, alcohol, and drug exposure

The greatest risk factors for infant bed-sharing death are maternal smoking during pregnancy, exposure to second-hand smoke after birth, and bed-sharing with an adult impaired by alcohol or drugs. A 2012 meta-analysis revealed 6.27 greater odds of death (95% confidence interval [CI], 3.94–9.99) while bed-sharing for infants of mothers who smoke versus an adjusted odds ratio (aOR) of 1.66 (95% CI, 0.91–3.01) for infants of non-smoking mothers (Vennemann et al., 2012). Two other large case-control studies have shown that smoking in combination with bed-sharing is extremely risky for younger infants (Blair, Sidebotham, Pease, et al., 2014; Carpenter et al., 2013). For infants younger than 3 months, the odds of death increased by a factor of 8.93 (95% CI, 5.27–15.14) in contrast to no significantly increased odds of deaths for infants older than 3 months sleeping next to a smoker (aOR 1.42; 95% CI 0.72–2.79) (Blair, Sidebotham, Pease, et al., 2014). Another analysis revealed a 65-fold adjusted increase in risk for 2 week-old infants bed-sharing when both parents had smoked (95% CI, 30.8–136.9), with decreasing risks with infant age (Carpenter et al., 2013). An analysis of SUDI deaths in New Zealand demonstrated that bed-sharing in combination with prenatal smoke exposure led to almost 33 times the odds of death (aOR 32.8, 95% CI 11.2–95.8) compared with infants bed-sharing with no prenatal smoke exposure (Mitchell et al., 2010). In this study, the combination of bed-sharing and prenatal smoke exposure was associated with 48% of the bed-sharing deaths (Mitchell et al., 2010).

Similarly, in SIDS data from New Jersey from 1996–2000, 93 out of 249 (38.9%) infants died while bed-sharing and only five (5.4%) had no major risk factors identified; 46.7% of bed-sharing deaths occurred in the context of maternal smoking and 40.0% had a smoking father

(Ostfeld et al., 2010). Among bed-sharing Black infants dying of SIDS in Chicago from 1993–1996, maternal smoking during pregnancy increased the odds of death by a factor of 4.0 (95% CI, 1.9–8.5) whereas infants of non-smoking mothers (aOR 1.9, 95% CI 0.9–3.8) or mothers who did not smoke during pregnancy (aOR 1.7, 95% CI 0.8–3.4) had no increased odds of death (Fu et al., 2010).

Caregiver drug or alcohol use before sleep was associated with a high risk of bed-sharing death but has not been measured in many studies (Blair, Sidebotham, Pease, et al., 2014; Carpenter et al., 2013). Mothers who bed-shared reported removing items from infants' airways during sleep and observations of mothers bed-sharing confirmed that they frequently responded when infants' airways were covered during bed-sharing (McKenna & Volpe, 2007). Infant death during bed-sharing may occur due to an impairment in caregiver response. In a study of infant sleep-related deaths in Victoria, Australia, from 2008–2010, 69.6% of the caregivers who were bed-sharing at the time of their infant's death admitted they had consumed alcohol and/or drugs before this last sleep (Bugeja et al., 2016). Blair et al.'s (2014) analysis revealed almost seven times the risk of death for infants sleeping with an adult who had consumed alcohol in the 24 hours prior to the last sleep as compared with non-bed-sharing infants with no other major risk factors. In another study, the risk of death for an infant sleeping next to a mother who had consumed alcohol was increased by a factor of 4.8 (aOR 4.8; 95% CI 2.6–8.9) (Carpenter et al., 2013).

Out of 33 bed-sharing deaths that occurred from 1999–2011 in Nunavat, Canada, over 70% involved more than one risk factor, which may have included alcohol consumption by the bed-sharing partner (Collins et al., 2012). Likewise, from 1992–2004 in Alaska, 99% of infant

bed-sharing deaths involved multiple risk factors and 43% involved a caregiver who admitted to alcohol and/or drug use before bed-sharing (Blabey & Gessner, 2009).

There are several issues with measurements of smoke exposure and drug and alcohol use. Only two studies (Mitchell et al., 2017; Vennemann et al., 2012) considered prenatal smoke exposure, although this has been shown to be a significant risk factor for infant death during sleep (Zhang & Wang, 2013). In addition, most studies do not quantify an amount of smoke exposure, although smoke exposure has been shown to have a dose-dependent effect on risk (Carpenter et al., 2013; Zhang & Wang, 2013). This may be true for alcohol use as well; these variables are difficult to define precisely within a multivariable risk model.

While several articles consider smoke exposure, many do not include alcohol and/or drug use by the infant's bed-sharing partner at the time of death (Fu et al., 2010; Mitchell et al., 2017; Ostfeld et al. 2010; Vennemann et al., 2012). Carpenter et al. (2013) found increased risk with caregiver alcohol and/or drug use, but their datasets measure these variables differently and only for the mother. Furthermore, 60% of these data were imputed. From 11 studies combined in a 2012 meta-analysis (Vennemann et al., 2012), there were no data on alcohol or drug use. For a long time, these data were not gathered accurately during scene investigations, but are now included as part of the standard form used to collect SUDI data in U.S. national and state programs (CDC, 2018).

To account for all major risks completely, studies would need to have data on prenatal smoking, second-hand smoke exposure in the home, alcohol use by the bed-sharing partner(s), and drug use by the bed-sharing partner(s). Although no study has ever completely accounted for all of these variations, one study's results suggested there was no increased risk of bed-sharing for infants with no tobacco smoke exposure sleeping with a caregiver who had not used drugs or

alcohol (Blair, Sidebotham, Pease, et al., 2014). In fact, this was the first study to show a possible protective effect of bed-sharing in infants over three months sleeping with unimpaired, non-smoking caregivers (aOR 0.1, 95% CI 0.0–0.5). Likewise, another study showed no increased risk of death for those older than three months without other major risk factors (aOR 1.0, 95% CI 0.3–3.0), but an increased risk of death for bed-sharing infants younger than three months (aOR 5.1, 95% CI 2.3–11.4) (Carpenter et al., 2013). In sum, there are few studies reliably supporting the claim that bed-sharing is dangerous for infants not exposed to tobacco smoke who are sleeping with unimpaired mothers.

Unsafe sleep space

Another major risk factor for infant bed-sharing death is sleeping in an unsafe sleep space. This includes sleeping on an arm chair or sofa, with heavy or excessive bedding, or on a soft mattress. The AAP acknowledged unsafe sleep space risks in the 2016 safe sleep policy statement, recommending that parents feed infants on a bed when there is a risk of falling asleep (AAP Task Force on SIDS, 2016). Bed-sharing advocates have described safe sleep spaces for bed-sharing parents (McKenna, 2020; Sears et al., 2005). These safe bed-sharing guidelines include removing the adult bedframe, ensuring the mattress is firm, eliminating heavy bedding, and placing the infant next to the mother and away from pillows.

In Blair, Sidebotham, Pease, et al.'s (2014) meta-analysis, the odds of death were increased 23 times (aOR 23.86; 95% CI, 52.2–109.2) when infants slept with an adult on a sofa or chair, while Carpenter et al. (2010) excluded infants found on non-bed surfaces from their analysis. Out of 33 "bed"-sharing infant deaths in Victoria, Australia, 12.1% occurred on a sofa (Bugeja et al., 2016), while 14% of bed-sharing deaths in Alaska from 1992–2004 were reported to have occurred on a sofa (Blabey & Gessner, 2009).

Fu et al.‘s (2010) analysis of infants in Chicago who died while bed-sharing showed an increase in risk with zero or one blanket in the sleep space (aOR 2.8; 95% CI 1.5–5.2). However, they also detected a decreased risk when greater than or equal to two blankets were present (aOR 1.8; 95% CI 0.8–4.1). In contrast, both a soft sleep surface (aOR 8.8; 95% CI 3.5–21.7) and pillow use (aOR 4.1; 95% CI; 1.4–11.5) showed increased odds of death while bed-sharing (Fu et al., 2010). Over 53% of bed-sharing deaths from 1996–2000 in New Jersey involved the presence of quilts, blankets, pillows, sofas, or other children (Ostfeld et al., 2010).

Volpe, Ball, and McKenna’s (2013) case studies of high-risk mother-infant co-sleeping analyzed mother-infant bed-sharing arrangements through direct observation. They discovered that mothers may succumb to the overwhelming drive for their own sleep in the middle of night, trading off known optimal infant sleep environments. These mothers slept with their young infants on a sofa, in bed with baby's head covered by blankets/pillow/hair, using multiple blankets and a baby pillow, and with continuous bottle propping and soft objects. These behaviors occurred despite education on safe sleep environments and despite being recorded (Volpe et al., 2013).

While this study described behavioral trade-offs, Baddock et al.’s (2012) and Ball’s (2009) observational studies examined particular risks in more detail. Baddock et al. (2012) recorded infants’ bed-sharing in their homes along with physiologic measurements. She monitored infant heart rate, oxygen saturation, and carbon dioxide rebreathing episodes to correlate these measures with behavioral events like head coverings. She found that bed-sharing infants had more desaturation events (<90%) per night compared with infants sleeping in separate cots (6.8 versus 3.1 events per night, risk ratio = 2.17 (1.75–2.69; $p<0.001$). She also found that increased infant core temperature correlated with desaturation events (Baddock et al.,

2012). However, in this group of low risk infants, there was no reactive elevated heart rate associated with the events. In addition, 22 bed-sharing infants had rebreathing events versus one cot-sleeping infant. There were no desaturations associated with these rebreathing episodes and most were associated with head covering (Baddock et al., 2012).

Ball (2009) has also measured infant heart rate, oxygen saturation, and airway covering events during bed-sharing. These studies showed that bed-sharing infants had their airways covered more than cot-sleeping infants (14/20 versus 2/20; Wilcoxon sign ranks test, p=0.006), but there were no instances of parents rolling onto infants and no significant differences in oxygen saturation or heart rate between bed-sharers and cot-sleepers (Ball, 2009). These studies may suggest that in some infants, these increased challenges may be enough to push their risk profile too far, whereas very low risk infants are able to respond to challenges immediately and effectively.

It is clear that to bed-share safely, the adult sleep environment needs to be adapted to the needs of the infant. Caregivers should ensure the mattress is firm, bottom sheet tight, and use one thin sheet or no blankets. Infants should be positioned away from pillows and should never sleep on sofas or arm chairs. In addition, to reduce the risk of suffocation and strangulation in bed, the bed should be removed from the frame, other furniture, and cords. Finally, the infant should sleep next to the primary caregiver only, preferably a breastfeeding mother.

No breastfeeding

Breastfeeding is protective of SIDS and breastfeeding mothers are more likely to bed-share (Ball et al., 2016). Breast milk composition studies have shown that infants should feed every 1–2 hours during each 24-hour period during the first few months of life, which suggests an adaptation to remain close to the mother in wakefulness and sleep (Elias et al., 1986). Ball

(2006) has shown that mothers who breastfeed and bed-share tend to sleep in a "C" shape surrounding their infant, with the infant's face at breast level and away from pillows. McKenna and Gettler (2015) have proposed the term "breastsleeping" to describe the orientation of a non-smoking, breastfeeding, intentionally bed-sharing mother and infant. They contend that this configuration is very different than in other bed-sharing situations and confers protection rather than risk during bed-sharing (McKenna & Gettler, 2015). Thus, lack of breastfeeding would be a risk factor for death during sleep in any situation, but especially when bed-sharing.

Overall, case-control studies have not adequately measured the effects of breastfeeding on bed-sharing risk. All of the studies measure breastfeeding differently, with some measuring whether the last feed was from the breast and others asking if the infant breastfed for at least 2 weeks after birth (Blair, Sidebotham, Pease, et al., 2013; Carpenter et al., 2013; Fu et al., 2010). Carpenter et al. (2013) report a slightly increased risk of death for bed-sharing infants who were not breastfeeding in their analysis (aOR 1.5; 95% CI 1.2–1.8). In Blair , Sidebotham, Pease, et al.'s meta-analysis (2014), breastfeeding was only significant for those not bed-sharing, but these infants seemed to be protected by breastfeeding (aOR 0.3; 95% CI 0.2–0.5). However, in Fu et al.'s (2010) case-control study of infants dying of SIDS in Chicago, lack of breastfeeding was associated with an increased risk of death compared with breastfeeding, bed-sharing infants (aOR 1.9; 95% CI 1.1- 3.4 versus aOR 1.1; 95% CI 0.3–3.4). Finally, over 40% of the 33 bed-sharing infant deaths from 2008–2010 in Victoria, Australia, were not among infants breastfeeding at the time of death (Bugeja et al., 2015).

Other factors influencing sleep-related death risk

For any future case-control study, multiple factors must be included, especially because there is still no consensus on the exact mechanism of death while bed-sharing. It is becoming clear that other factors in combination with bed-sharing may be responsible for the increased risk, but infants less than 3 months may be at a greater risk for death while bed-sharing regardless of risk profile. Carpenter et al. (2013) and Vennemann et al.'s (2012) studies showed increased risks with bed-sharing in those less than three months of age, but non-significant risks for infants greater than three months of age. Again, the data on alcohol use were either mostly imputed or missing in some of the datasets, while some smoking data were either imputed or limited to just maternal use (Carpenter et al., 2013; Vennemann et al., 2012). Blair et al.'s (2014) results for bed-sharing infants less than 3 months of age were non-significant but showed a possible protective effect of bed-sharing for infants older than 3 months of age, while accounting for smoking and alcohol use by parents (aOR 3.3; 95% CI 2.1–5.3 versus aOR 0.1; 95% CI 0.01-0.5). This lack of support for bed-sharing risk in those greater than three months of age should be explored further.

Limitations and gaps of bed-sharing risk studies

There are many limitations inherent in these studies. One of the most obvious is the difficulty in gathering rigorous data. For most of the studies, families are visited for interviews and scene re-creation with dolls within 24 hours to one week of the sudden death of their infant (CDC, 2018). Investigators must rely on these bereaved families to provide accurate information. While some countries have enacted rigorous, standardized reporting measures, others are just now working on this, making these analyses even more complex (CDC, 2018). Trends in defining SIDS greatly influence the categorization, thus subsequent analysis of these deaths

(Beckwith, 2003). For years, SIDS and presumed asphyxial modes of death were often labeled interchangeably, and there have been greater efforts recently to establish standardized criteria for assignment. One of the most significant results of this is that many deaths labeled SIDS actually appeared consistent with asphyxia (parent awoke on top of the infant, for example), but may not have been labeled as asphyxia due to the inability to prove this as the cause of death (Beckwith, 2003). Recent efforts have been aimed toward the correct labeling of these deaths, to reduce the possibility that deaths actually resulting from asphyxia are not confused with SIDS (Krous et al., 2004).

Problem statement and purpose of this manuscript

Despite warnings that bed-sharing may place infants at risk of death, parents still bed-share. The difference between professional advice and parental practice hampers communication and halts understanding of the underlying issues. Part I of this manuscript consists of an article that provides a nursing perspective on infant bed-sharing using multidisciplinary theory integration. This will provide a broad framework for understanding the research that has been done on infant bed-sharing in multiple disciplines. Part II of this manuscript contains a systematic qualitative meta-synthesis of infant-caregiver bed-sharing experiences across the world. Reasons and experience of bed-sharing are complex and differ depending on culture and family values, so it is vital for researchers and providers to understand the prevailing practices and viewpoints of families in their region. For providers working in Appalachia, there is no research to provide this perspective. Thus, Part III of this manuscript presents the results of a narrative inquiry that examined the experience of caregivers from Southern and South-Central Appalachia who shared a bed with their infants.

Appalachia

Despite calls for examination of infant bed-sharing in particular sub-cultures, there is little evidence about infant sleep practices in the Appalachian region of the U.S. Appalachia is an area of the Eastern U.S. comprising 13 states and 450 counties, stretching from New York to Mississippi (Appalachian Regional Commission [ARC], 2020). It is defined by the mountainous areas of the Appalachian mountain range, which historically placed a barrier between the inhabitants and the rest of the economic world. As industrialization occurred and the shift away from coal commenced, the area experienced economic depression (Russ, 2010). Historically, the inhabitants of the area came from the Scottish and Irish highlands, and in some areas, Scottish and Irish cultural values have been preserved (Russ, 2010). While some scholars debate whether there is a defined "culture of Appalachia," most still see value in studying the region and point out that there are defining cultural values that still strongly stand in some areas despite modernization (Denham, 2016). These values include familism, Evangelical Protestantism, valuing place, interdependence, and community loyalty (Denham, 2016; Russ, 2010).

Admittedly, there are countless sub-cultures and many areas that would not appear to match these descriptions of Appalachia at all. In the study presented in Part III, it is assumed that there is some cultural integrity to the Appalachian region, thus it would be valuable to study the experiences of caregivers from this region and present their voices. At the same time, there is an acknowledgment of the diversity of Appalachia and the possibility that there will be few commonalities in each of the participant's experiences.

Because the infant bed-sharing debate centers around risks of infant sleep-related death, it is important to note that infant mortality rates are higher in Appalachia than they are in any other U.S. region (PDA, Inc, The Cecil G. Sheps Center for Health Services Research, & ARC, 2017).

This rate includes infant sleep-related deaths. Thus, this is an area heavily targeted for anti-bed-sharing and safe-sleep messaging. The social and political implications of this include a possible mismatch between familial values and public health goals. It is difficult to understand these complex interactions without speaking directly to the families involved with the issue.

Research questions

The main research questions for this study were: What was the experience of caregivers in Appalachia who shared a bed with their infant? Sub-questions included:

- What was the meaning of bed-sharing for caregivers in Appalachia?
- What were Appalachian caregivers' motivations for bed-sharing with their infants?
- What were Appalachian caregivers' feelings about the infant bed-sharing experience?
- What can Appalachian caregivers' experiences, meanings, motivations, and feelings about bed-sharing with infants teach nurses and other health care professionals?

Definitions

The following definitions were used in this study, despite the recognition that these definitions may not be the most appropriate for use in other situations and do not constitute "true" or the only definitions of these terms. For all of the following definitions, the participant decided whether the definition applied.

- *Caregiver* - the self-defined primary night-time caregiver of an infant
- *Infant* – a child between the ages of 0 to 12 months
- *Bed-sharing* - a caregiver and infant sharing the same sleep surface. In the U.S., this surface is most commonly an adult mattress situated on a raised frame, often with a head and footboard. Bed-sharing may or may not include other members of the family, such as the father, grandparents, or siblings.

- *Regular bed-sharing* –the caregiver and infant must have shared a bed at least 4 hours every night, 5 days every week for at least one month of the infant's first 12 months of life
- *Southern or South-Central Appalachia* –participant identifies as being from a county in one of these regions

Philosophical perspective

The philosophical perspectives underlying narrative inquiry (NI) are complex and contested. Most scholars of NI agree that the use of narrative for research purposes began to grow in the 1960s and fully blossomed in the late 20th century (Andrews et al., 2013; Pinnegar & Daynes, 2007). The turn away from positivistic and realist views to postmodernism and a focus on the "self" made a path for NI to flourish as a methodology that would cross disciplinary boundaries. Clandinin and Rosiek (2007) discuss "borderlands" of NI, which include post-positivism, Marxism, and post-structuralism. These philosophies are borderlands to Dewey's pragmatism, which can guide an approach to experience and exploration of this experience through narrative (Clandinin & Rosiek, 2007).

NI is a qualitative research method and shares relativistic and anti-positivist views. This philosophy includes the idea that there is no "truth" apart from individual context and perception. Thus, the best way to understand the world is through the meanings and perspectives of the people experiencing the phenomena. For narrative inquirers, this meaning is revealed and created through experience, which can be explored through story. Story, or narrative, is not the direct reflection of experience, but is another interpretation and means to communicate experience with another person (Clandinin & Rosiek, 2007). Through interaction, the story itself becomes

something apart from the experience it seeks to reflect and is affected by the relationship with the environment, including all of the individuals involved in the exchange of story.

Pragmatic philosophy does not seek to make claims about truth outside of context. Instead, it is experience, testing, and re-experiencing that matter. Given that our conception of the world hinges on experience, it is all that matters (Hutchinson, 2015). William Pierce and John Dewey are considered pioneers of pragmatism, although they take different viewpoints (Buckingham et al., 2011). A Deweyan view of experience provides the frame for NI in this study. Dewey's theory of experience rests on the three-dimensional spaces of temporality, sociality, and place (Clandinin & Rosiek, 2007). Experience is continuous; our experience is grounded in what has come before, what is presently occurring, and our future is experienced in the light of these previous experiences. Thus, we live in a continuous stream of interlocking experiences. Likewise, experience is transactional (Clandinin & Rosiek, 2007). Experience cannot be separated from the transaction between intrapersonal, interpersonal, cultural, familial, and organizational (Clandinin & Rosiek, 2007). Place is always important, as it is a part of the transactional that always informs and is informed by our experience (Clandinin & Rosiek, 2007). The narrative inquirer working from a Deweyan ontological understanding is always interacting within this three-dimensional space with participants (Clandinin & Rosiek, 2007). All interactions are also part of the experience being reflected upon; thus, NI is the phenomenon and the methodology.

A NI approach is used in this study to examine bed-sharing experiences because a pragmatic, Deweyan view of experience pre-supposes that experience is best understood through narrative, as experience is narratively composed by individuals (Clandinin, 2016). This view has been neglected in the examination of bed-sharing, with only a few studies using a narrative

approach (McKenna & Volpe, 2007). This is unfortunate because caregiver-infant bed-sharing is ultimately an experiential phenomenon and studies suggest some of the main issues in modern debates about bed-sharing involve a misunderstanding of parental experience in context. Furthermore, nursing is a relational, caring, person-centered profession and revolves around the use of narrative to understand patients' lives (Smith & Liehr, 2005). Nurses use stories to understand patient problems, health deviations, and to construct therapeutic plans. Thus, NI is a well-suited methodology for understanding nursing problems. Finally, the Appalachian region of the U.S. has a strong story-telling heritage. One of the main story-telling capitals of the world is located in a South-Central Appalachian county (International Storytelling Center, 2020). Thus, one of the assumptions about the Appalachian region is that individuals will be naturally acquainted with traditional storytelling, which is the main source of data in NI. These are some of the reasons for the selection of a NI approach to the study of bed-sharing among caregivers from Appalachia.

Assumptions

Assumptions arising from Dewey's pragmatic theory of experience within NI include the following (Clandinin & Rosiek, 2007):

- Any reality outside of experience is unknowable and irrelevant
- Experience is formed narratively and narrative is experience itself, rather than a less than ideal way to represent an outside reality
- Experience is continuous, being influenced by past, present, and future
- Experience is transactional, embedded in and influenced by the environment

- Researchers cannot separate their realities from that of the participants and, thus, must include their own influence on their participant's narratives and the participant's influence on the researcher's ever-changing narrative in the study

Limitations

The limitations of NI as a methodology center around the philosophical perspective behind NI. NI is an inherently interpretive methodology. Narrative inquirers work from the viewpoint that the individual's story is a phenomenon worth exploring in itself, such that NI is both the phenomenon of study and the method. The limitations involve the ideas about the meaning and function of personal story. Polkinghorne (2007) points out that narrative methodologies are limited in many ways, including differential effects of researcher-participant interaction. Narrative inquirers admit that researchers affect the types of stories told and how these are told. They do not attempt to bracket this influence out of the study, but try to remain open about this influence, integrating it into the analyses. Social desirability bias must always be considered; participants may alter what parts of the story they tell. There are also restrictions imposed on the use of language to express experience (Polkinghorne, 2007). Some contest that language is only a reflection of experience, or another representation of some other "pure" concept. Others look at story as the way all of life is experienced, so that the telling and re-telling shape and become the actual substance of the experience (Clandinin, 2016). These nuances in understanding about what can be known through story affect how expansive or how limiting one views results of NI studies. Ultimately, the limitations imposed by NI are accounted for by considering these within the analyses. The researcher must constantly work within the multi-dimensional space around themselves, the participants, and the environment, and consider multiple factors at once to produce a full analysis of the resultant stories.

Delimitations

The delimitations of this study include several participant requirements. The sample was limited to primary night-time caregivers from Southern and South-Central Appalachia to gain insight into the practice in this geographical area, but also provide some limits given that the Appalachian region is vast. Southern and South-Central counties were chosen because of convenience and the high rate of SUDI in some of the counties in this region (CDC, 2019). The participants must have shared a bed with their child regularly because this experience was the target of this study, not occasional bed-sharing. The participants must also have shared a bed with the infant within the past 5 years in an attempt to get stories from caregivers who have recently experienced bed-sharing in a similar historical context in the U.S. Finally, this study purposively restricted what kind of story was told because the participants were asked specifically about infant bed-sharing. This could have been approached more widely, with the researcher asking about the experience caring for an infant more generally or the experience dealing with infant sleep, but in this study, the purpose was to get at the center of the actual experience of bed-sharing. However, by purposefully asking about bed-sharing, it likely did alter what the participant told or remembered as most important in their story of caring for an infant.

Significance of the study in Part III

There is a large body of research about bed-sharing. However, the voices of caregivers who bed-share are relatively absent within this literature. There are no studies that give a voice to caregivers from Southern or South-Central Appalachia. This region has higher health risks in many areas, including infant mortality, compared with the rest of the U.S. (Singh et al., 2017). It is also a region recognized as having unique sociocultural characteristics (Denham, 2016). Therefore, it is difficult for providers or public health professionals to provide effective advice to

this group without understanding their experiences of bed-sharing. Currently, the AAP recommends all providers take a firm anti-bed-sharing stance, regardless of cultural environment (AAP Task Force on SIDS, 2016). However, these recommendations are only helpful if they fit into the lives of the people served. Understanding the stories of caregivers in Appalachia who have shared a bed with an infant will give insight into the importance and multi-dimensionality of the practice, allowing providers to make particular considerations when speaking with families. Furthermore, this information may open up new channels to be explored within epidemiologic research.

There have been no studies of caregiver-infant bed-sharing using NI, despite the experiential nature of the practice. Nurses use narrative in everyday practice, gathering stories from patients to tend to holistic needs. For many individuals, bed-sharing becomes a personal, anxiety-producing practice, entrenched with secrecy and the feeling of failure for succumbing to the temptations to bring the baby into bed. It seems that story is the central feature of this sensitive topic, and it is important to formalize those stories to see what might be learned.

This manuscript is divided into three parts and is designed to provide a holistic overview of several facets of the bed-sharing debate. Part I includes a manuscript examining the theoretical perspectives underlying studies of infant bed-sharing. This analysis reveals the reasons this debate is so complex and calls for collaboration and melding of different theories going forward. Part II consists of a systematic qualitative meta-synthesis of current research about caregivers' experiences bed-sharing. Part III contains the results of a narrative analysis of caregiver-infant bed-sharing in Southern-Central Appalachia. Finally, the conclusion presents interpretations of this research as it relates to the body of knowledge as a whole, as well as the significance to nursing practice, research, and policy.

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PART I: A NURSING PERSPECTIVE ON INFANT BED-SHARING USING MULTIDISCIPLINARY THEORY INTEGRATION

Part I was submitted to *Advances in Nursing Science* by Marissa Bunch and Sadie Hutson. Marissa Bunch is the primary author and conceptualized and planned the article. Sadie Hutson gave significant input, editing, and final approval of the manuscript. The article is included here as submitted to the journal, with some changes in formatting.

Abstract

The American Academy of Pediatrics recommends against any bed-sharing between infants and caregivers due to an association with suffocation. Caregivers continue to share a bed with their infant despite these recommendations. A close examination of the bed-sharing literature reveals that the debate is fundamentally about theoretical differences. The major theories used to frame this problem include the triple risk model of bed-sharing and evolutionary theories. Nurses are masters of multi-disciplinary collaboration and are well-positioned to unify the triple risk and evolutionary views of infant bed-sharing to guide future innovations in health care practice and research.

Keywords: sudden infant death syndrome, SIDS, sudden unexpected death in infancy, SUDI, bed-sharing, co-sleeping, breastsleeping, evolutionary theory, nursing, triple risk model

Introduction

Mothers and infants have slept in close contact in most of the world throughout history. However, case-control studies have revealed an association between bed-sharing and sudden unexplained death in infancy (SUDI), leading professional organizations to develop anti-bed-sharing policies (American Academy of Pediatrics [AAP] Task Force on Sudden Infant Death Syndrome [SIDS], 2011). In 2016, the AAP revised safe sleep guidelines to recommend same-room but separate-surface sleep for infants (co-sleeping) (AAP Task Force on SIDS, 2011). The AAP admitted that bed-sharing may not be dangerous in all situations; in fact, some countries with a high prevalence of bed-sharing have had very low infant sleep-related death rates (McKenna, Ball, & Gettler, 2007). This discrepancy may be attributed to risks inherent in the western sleep environment (ie, heavy bedding, soft mattresses, smoking).

Research on maternal-neonatal separation has shown that absence of maternal contact in the first few weeks of life is a significant stressor for the newborn (Gunnar & Quevedo, 2007). Other socio-emotional benefits to bed-sharing have been suggested, including enhanced attachment security and neurodevelopment (Mileva-Seitz et al., 2016). In addition, breastfeeding mothers often choose to sleep with their infants as a practicality or inadvertently fall asleep while breastfeeding (Mileva-Seitz et al., 2016). The high rates of accidental bed-sharing and these socio-emotional considerations make it important to determine whether bed-sharing is dangerous in the absence of risk factors.

Scholars must carefully review recommendations when public health campaigns prove to be difficult for parents to follow. Most scholars questioning the anti-bed-sharing messages have viewed the issue using evolutionary theory and have emphasized that the infant evolved in an "environment of evolutionary adaptedness" that included bed-sharing (Bowlby, 1982). Thus,

they have hypothesized that safe bed-sharing should lead to healthy socio-emotional and physical development (McKenna, Ball, & Gettler, 2007). Others have focused on the correlated risks between bed-sharing and death and have overlooked the infant's adaptations, which most obviously show up in the need to breastfeed and to be comforted several times during the night. Caregivers must respond to the infant's needs in ways that also preserve their own health and allow for sleep and stress regulation. Epidemiological models of bed-sharing have been the most common framework for examining risk and have been the basis for state and national policies recommending wholly against bed-sharing; yet, they have failed to acknowledge parental decision-making around bed-sharing.

Researchers working from both evolutionary theories and the risk models of epidemiology must work to bridge theoretical gaps and resolve this debate. This paper will address the major theories used to frame the debate about bed-sharing. Further, the authors suggest that nurses are well-positioned to advocate for a holistic view of the bed-sharing problem using theory integration.

The triple risk model of bed-sharing: Tenets, assumptions, and paradigm

Much of the impetus for the anti-bed-sharing campaign comes from epidemiologic studies, specifically population-level case-control studies and retrospective death reviews. While epidemiological studies make a significant impact on population health, scholars must also examine the theories behind the methods in order to determine control variables and interpret results. Even so, it is difficult to quantify the individual degrees of risk experienced by each infant in combination with the considerations made by parents. Furthermore, case-control studies cannot provide explanations regarding increased risk when it is present. Epidemiologic theory often consists of various models of disease causation. The most well-known medical model of

SIDS causation is the triple risk model of SIDS (Guntheroth & Spiers, 2002).

The triple risk model of SIDS has undergone several iterations since it was first developed (Guntheroth & Spiers, 2002). This model states that infants who die of SIDS have some combination of an underlying pathophysiologic deficit, a vulnerable developmental period, and an external stressor (Guntheroth & Spiers, 2002). In the most popular form of the triple risk model, Filiano and Kinney (1994) suggested that susceptible infants sustain prenatal injury to the brainstem leading to cardiorespiratory regulation failure. This model proposes that when SIDS occurs, the infant is usually in a vulnerable developmental period (2-4 months) in which homeostatic regulatory processes are not functioning at their highest level. Finally, an exogenous stressor, such as re-breathing carbon dioxide or overlying by an adult, pushes the infant into a cycle leading to the inability to halt apnea and bradycardia (Filiano & Kinney, 1994).

Population level case-control studies of sleep-related infant death examine several of these risk factors (Blair et al., 2014; Vennemann et al., 2012). However, studies have only recently considered other important risk factors, like place of sleep (sofa, chair, bed, floor), parental drug and alcohol use, and whether the infant was breastfed. In fact, only one large case-control study has incorporated parental drug and alcohol use among breastfeeding infants and this study has been criticized for imputing 60% of the parental drug and alcohol data (Carpenter et al., 2013).

Byard (2012) called for a new conceptualization of epidemiological research on bed-sharing deaths through a triple risk model of bed-sharing, based on the triple risk model of SIDS first proposed in the 1970s (Byard, 2012). This model suggests that a bed-sharing infant is at risk due to three interrelationships: infant vulnerabilities (prematurity, age, weight), bedding environment (soft surface, heavy blankets, entrapment risk), and caregiver (intoxicated, smoker,

obese) (Byard, 2012).

Byard (2012) admitted that epidemiologic studies have not always supported bed-sharing as an independent risk for infant death. For example, some studies reported an increased risk of death associated with bed-sharing while including sofa and chair sleeping in this group (Carpenter et al., 2013; Vennemann et al., 2013). Thus, it was unclear whether bed-sharing was the reason for death or the manner in which caregivers and infants bed-shared. One major case-control study did not control for alcohol use among bed-sharing parents and none of the studies had adequate data on caregiver drug use (Vennemann et al., 2013). Bed-sharing may not be an exogenous stressor in the triple risk model unless confluent with other major risk factors. These factors may include a caregiver who bed-shared and smoked pre- or postnatally, was impaired by drugs or alcohol, or bed-shared on a sofa.

The implication behind the various formulations of the triple risk model is that parents make either risk-prone or risk-averse decisions about interactions with their infants. The studies imply that if risk factors are identified, caregivers will be able to eliminate those factors, thus minimizing or eliminating the risk for sleep-related infant death. Almost all large case-control studies on infant bed-sharing death conclude with admonitions that caregivers should not smoke, use drugs or alcohol, or bed-share because of the clear risk of death. There is rarely any discussion of the complex biocultural contexts of these decisions.

Epidemiological theories like the triple risk model of bed-sharing are situated within the positivist philosophical paradigm. This paradigm centers on scientific, objective knowledge and assumes there is an objective nature of reality which can be determined through experimentation. There is not much room for individual nuances and subjective experiences are overlooked in favor of objective, measurable phenomena. There is certainly a place for positivist paradigms in

research; epidemiologic studies have led to great declines in infant deaths. However, recent interventions have not led to major declines in sleep-related death (Hunt et al., 2014). An interdisciplinary consideration of all the theories behind infant-caregiver bed-sharing is needed to re-evaluate interventions to impact the sleep-related SUID rate. The interdisciplinary consideration of multiple theories will necessitate conversations between many disciplines including nurses, public health workers, epidemiologists, health care providers, child and family developmentalists, and anthropologists.

Evolutionary theories of bed-sharing: Tenets, assumptions, and paradigm

Evolutionary theories contain elements of many philosophies. Looking back from Darwin, numerous philosophers speculated on the interconnectedness of nature. The notion that the universe is made of one elemental substance (Thales, Parmenides, Democritus) parallels Darwinian ideas that modern humans ultimately evolved from the same simple life-form (Buckingham et al., 2011). Likewise, Aristotle's focus on taxonomy foreshadowed much of Darwin's work (Buckingham et al., 2011). In contrast, the assumptions of evolutionary theory stand in sharp contrast to Locke's idea that humans are born as a "tabula rasa" (Buckingham et al., 2011). For example, evolutionary psychology theories propose that infants already possess evolved psychological modules for solving problems at birth (Bjorklund & Pellegrini, 2000).

Studies on maternal-neonatal separation, skin-to-skin contact, and breastfeeding have supported many evolutionary hypotheses (Gunnar & Fisher, 2006; Morgan et al., 2011). Some of the most well-known studies on bed-sharing mother-infant dyads were framed by evolutionary theory (McKenna, Ball, & Gettler, 2007). James McKenna and Helen Ball lead the two foremost co-sleeping research labs in the world and they are both anthropologists, working from the assumptions of evolutionary theory (McKenna, Ball, & Gettler, 2007). McKenna has spent his

research career expounding on his hypothesis that bed-sharing can be protective of SIDS (McKenna, Ball, & Gettler, 2007). In several articles, he explained how parental breathing cues and physiologic synchrony combine with a lowered arousal threshold to protect the infant from death during sleep (McKenna, Ball, & Gettler, 2007). This hypothesis relies on the assumption that this adaptation emerged over millions of years to create an "expected environment" for the infant.

McKenna studied maternal-infant pairs in a sleep lab out of Notre Dame beginning in the early 1990s. His research group found that bed-sharing mothers and infants spent much of the night in the same sleep states and more of the night in light sleep compared to when they were sleeping separately (McKenna, Ball, & Gettler, 2007). McKenna's evolutionary conceptual framework about SIDS guided and was refined by these studies and influenced further anthropological research in the area (McKenna, Ball, & Gettler, 2007).

Helen Ball also operates from an anthropological, evolutionary framework to examine breastfeeding in relation to co-sleeping between parents and infants (Ball et al., 2006). In her direct observational studies of co-sleeping infants, she has shown that bed-sharing infants breastfeed more often than separate sleeping infants with few airway covering events and no near-fall events (Ball et al., 2006). She has argued that separating infants, feeding artificial milk, and using sleep aids like pacifiers effectively leads them into an inappropriate deep sleep without protective mechanisms, predisposing these infants to SIDS (McKenna, Ball, & Gettler, 2007). Finally, McKenna and Ball have shown that in many cultures with high rates of sleep-surface sharing, SIDS rates are very low (Task Force on SIDS, 2011).

Ball has described a characteristic, protective orientation that breastfeeding mothers assume when they sleep with their babies (Ball et al., 2006). They orient themselves with the

infant at chest level, away from the pillow with the mother on her side with legs curled up underneath and arm over top of the infant (Ball et al., 2006). According to Ball's studies, when infants were not breastfed, they were often placed on a soft, adult pillow in the direct path of the mother's expired air (Ball, 2006). Baddock noted similar orientations in her studies in infant-parent homes (Baddock et al., 2007). She noticed breastfeeding increased with bed-sharing and although there were more airway covering events in bed-sharing groups, there was no physiologic compromise in these cases (as measured by oxygen saturation, apneic events, and heart rate variability) (Baddock et al., 2012).

Life history theory

Ball, Volpe, and McKenna have examined bed-sharing using life history theory, a specific evolutionary theory that emphasizes the transactional processes that occur as parents subconsciously balance their own survival needs with those of their children (Volpe et al., 2013; Gettler & McKenna, 2010; Volpe, 2010). Volpe (2010) found that adolescent and adult mothers made risky decisions about sleep environments, each trading their own needs for those of their infant. Often, the adolescents balanced their needs for sleep with their infant's nighttime demands through increased proximity, including bed-sharing. While adult mothers also placed infants in unsafe environments (multiple blankets in cribs, for example), they more often used distancing to separate themselves from the infants. Volpe concluded that individual mothers make highly nuanced decisions about parenting based on their own life trajectory, balancing their own survival needs with that of each individual child (Volpe et al., 2013; Volpe, 2010).

Predictions made by the triple risk model of bed-sharing

The triple risk model of bed-sharing assumes that families can make decisions based on straight-forward risk mitigation. The assumption arising from the theory is if certain risk factors

are eliminated, infants will not die during sleep. This is an overly simplistic, straight-forward approach that says, "if only caregivers would stop smoking/bed-sharing/placing infants on soft surfaces," infant deaths would cease. While the triple risk model is not directly used to predict caregiver bed-sharing decisions, it is subtly used this way. For example, two predictions for why and how caregivers bed-share are:

- If caregivers are made aware of the important risk factors for sleep-related death, they will eliminate these risk factors.
- Caregivers will rely upon scientific evidence from the academic community to make decisions, uninfluenced by their biocultural or sociopolitical environment.

Thus, widespread public health campaigns tout the "ABC"s of safe sleep (Alone, on the Back, in a Crib) which do not address the mother sleeping with her baby to keep her warm because the apartment has no heat or the parents whose parents, grandparents, and great-grandparents slept with their children due to a strong belief in family interconnectedness. Caregivers must believe that the risk factors identified in complicated statistical analyses are going to prevent their infant from dying when their instincts tell them otherwise. James McKenna has shown that many mothers have stories about terminating a life-threatening event for their infant because they were sleeping together (McKenna & Volpe, 2007). For example, one mother said she woke up to find her infant was not breathing. When she moved the infant, she said the baby began breathing again; she was convinced she had saved the infant's life. Whether these are accurate experiences or not, they are powerful emotional stimuli to motivate caregivers to continue bed-sharing despite epidemiological evidence and adamant public health campaigns.

Predictions made by evolutionary theory

Separating breastfeeding and sleep is difficult. The composition of breast milk is such that infants need to feed every 1-2 hours in the first three months of life (Jones, 1974); multiple studies of hunter-gatherers have confirmed an average hourly breastfeeding rate that depends upon constant contact between mother and infant (Buswell & Spatz, 2007). If a mother intends to breastfeed exclusively, frequent milk removal stimulates the firm establishment of breast milk supply (Wombach & Riordan, 2016). In addition, the neonate's small stomach and labile blood glucose demand near-constant feeding (Wombach & Riordan, 2016). Separate sleep in this setting is difficult.

Evolutionary theory predicts that caregivers should seek close proximity to their infants in the first months of life. This proximity should lead to healthy attachment and provide the safety and warmth of physical and emotional closeness. Two specific predictions regarding caregiver bed-sharing influenced by evolutionary theory include:

- Caregivers will feel a strong internal need to be near their infants during sleep and will tend to fall asleep with their infants regardless of initial intention. Likewise, infants who bed-share in the first year of life will show more secure attachment security and developmental resilience than infants who sleep alone.
- Mothers who breastfeed will be more likely to bed-share with their infants and there should be no increased risk of death in infants sleeping with unimpaired breastfeeding mothers on a firm sleep surface.

Maternal-neonatal separation

There is a large body of research examining infant stress regulation related to maternal-neonatal separation, which has obvious implications for bed-sharing (Gunnar & Quevedo, 2007).

The measurement of salivary cortisol was used to quantify stress response in these studies because there have been no consistent direct behavioral correlates to hypothalamic-pituitary-adrenal (HPA) axis activity (Jansen et al., 2010). Secondary stress measurements include heart rate variability and assessments of pain and motor activity (Morgan et al., 2011). Observations of bed-sharing remain challenging, so these measures are most easily obtained from solitary sleeping infants, especially babies in the neonatal intensive care unit. Some preliminary studies showed increased cortisol reactivity for solitary sleeping babies, and several studies confirmed long-term epigenetic and mental health disadvantages associated with maternal-neonatal separation (Hostinar et al., 2014; Waynforth, 2007). Morgan, Horn, and Bergman found a 175% increase in heart rate variability power when neonates slept alone, indicating higher stress reactions with maternal-neonatal separation versus skin-to-skin contact (Morgan et al., 2011).

In her comprehensive review of bed-sharing research, Ward (2015) found that breastfeeding was the most common reason for bed-sharing. In fact, even in areas where anti-bed-sharing campaigns were rampant and harsh, many mothers still bed-shared with their infants, whether they intend to or not (Smith et al., 2016). Bed-sharing rates are increasing, but caregivers do not disclose this practice to health care providers because they know bed-sharing is considered to be dangerous (Colson et al., 2013; Wert et al., 2015). Caregivers continue bed-sharing even when they know the risks and express a desire to receive advice on safe bed-sharing (Ateah & Hamelin, 2008). However, health care providers are unlikely to provide this advice because they fear supporting a practice that has been linked with infant death.

Attachment theory

Attachment theory arose from evolutionary and human behavioral ecology models. Bowlby and Ainsworth placed importance on maternal responsiveness and proximity-seeking

and strongly rejected the notion that responses to crying perpetuate negative behavior (Bowlby, 1980). Evolutionary models suggest that babies who are most successful in getting a response when proximity-seeking should be the most likely to survive (Bowlby, 1980). Thus, Bowlby and Ainsworth reasoned that maternal responsiveness would foster secure attachment and optimal development in the child. Iterations of attachment theory, including the "attachment parenting" movement, have clearly supported safe bed-sharing as an important part of maternal responsiveness, bonding, and breastfeeding (Bowlby, 1980).

Like maternal-neonatal separation studies, attachment theory seems to lead to the hypothesis that proximity during sleep would lead to secure attachment, as bed-sharing facilitates response to infant cues and on-demand breastfeeding. In fact, this is what many attachment parenting and breastfeeding proponents claim. Mileva-Seitz et al. (2016) found that infants who slept solitarily (vs. bed-sharers) were more likely to have a lower attachment security score. Although a secure attachment does not override the need for the infant's safety during sleep, it is an important consideration in the bed-sharing controversy. If mother-infant bed-sharing is important to attachment security, it is even more important that risks are carefully quantified.

Breastsleeping

McKenna and Gettler (2015) proposed use of the term "breastsleeping" to define low-risk breastfeeding mothers sharing a sleep surface with their infants. The term is important because the studies that have been used to make anti-bed-sharing recommendations so far have grouped low risk mother-infant pairs with all other bed-sharing infants, precluding the important confounding factors that make bed-sharing unsafe (McKenna & Gettler, 2015).

The term "breastsleeping" was inspired by Mobbs et al.'s (2015) article on "imprintment, latchment, and displacement." They proposed a model of human infant imprinting in the first

hour of life. After birth, the infant is drawn to the mother's nipple through oral tactile Merkel cell mechanosensors which are connected to the sensory cortex and facilitate teat imprinting. Their model hypothesized that human infants deprived of constant maternal skin-to-skin contact and constant access to the nipple ("mother in the mouth") experience displacement, or transfer of the imprint to a decoy (finger, pacifier, or bottle nipple), which does not confer the same neuronal, immunologic, and hormonal benefits as mother's nipple. These authors directly connected successful latch and imprinting with safe bed-sharing because constant nipple access is so vital to early breastfeeding success and attachment security (Mobbs et al., 2015).

Analyzing bed-sharing using theory integration

Currently, epidemiologists have represented the triple risk model of bed-sharing as a two-dimensional Venn diagram and continuum. This model could incorporate McKenna and Gettler's (2015) proposal that low risk breastsleeping mothers sleeping next to their baby in a prepared environment might be protective against death while also including all the modifiable risk factors that increase risks. Exclusive breastfeeding does not negate the importance of an unimpaired mother and a firm mattress without heavy bedding or smoke exposure. The risk-benefit continuum includes several factors, including infant age, weight, and environment (Byard, 2012). One conceptualization of the breastsleeping concept combined with the triple risk model of bed-sharing is displayed in Figure A.1. There is some support for this model coming from anthropology and epidemiology. It is difficult to quantify the risks of each situation, which is why the diagram is in two intersecting dimensions. In order to advance this discussion, researchers will need novel methods of testing this model.

Implications for research and practice

Bed-sharing safety is about more than the thousands of infants that die during sleep every year. It is also about intuition and choice. Every family birthing a child faces this issue and they are often given a message that is difficult to align with daily life. If researchers find that all bed-sharing deaths involve one or more major risk factors, the low risk breastsleeping concept will gain support. The public health department in Alaska supports bed-sharing with non-smoking, non-impaired caregivers, yet 99% of bed-sharing infant deaths from 1992 – 2004 included at least one other major risk factor and often more than one (Blabey & Gessner, 2009). Further studies may reveal the same multiple-risk profiles of bed-sharing infant deaths.

Some risk factors will always be difficult to quantify. Individual infant vulnerability has been explained in many ways, including brainstem and genetic abnormalities (Guntheroth & Spiers, 2002). The SIDS risk continuum includes the hypothesis that there are some pathologies that only lead to death under particular stressors (Ball, 2006). From an evolutionary perspective, those infants with underlying vulnerabilities would not have been as noticeable in the "environment of evolutionary adaptedness" due to the high rate of infant mortality overall (Bowlby, 1982).

Researchers in human behavioral ecology work from an evolutionary perspective but emphasize the variation among humans (Kaplan, 2000). Cultural evolutionists emphasize the interplay between biology and culture. The issue of breastsleeping straddles the biology-culture divide because infants require frequent feedings throughout the night. A multi-disciplinary approach to this problem is possible if the triple risk model of bed-sharing is super-imposed on a breastsleeping model. If studies cannot support any safe bed-sharing situation, the evolutionary theorists and triple risk theorists may consider a compromise. Separate surface, cot-side, or in-

bed sleepers may facilitate breastfeeding and prevent accidental bed-sharing; studies must be done to validate the effectiveness and safety of these devices (Ball et al., 2006).

Conclusion

Bed-sharing is common, despite great efforts to reduce its incidence. The predominant tone over the past three decades has been one of strict, blanket, anti-bed-sharing rhetoric. The contrast of policy versus practice has led to confusion, guilt, and tragedy within families. It is time to expand bed-sharing theories to make room for the complex nuances apparent in a diverse context. Nurses are well-positioned to lead this initiative. Nurses can advocate for caregivers by listening to their stories and developing solutions alongside families. Nurses must communicate with families in an honest, non-judgmental manner and remain open to discussing ways to make bed-sharing safe. When bed-sharing cannot be practiced safely, nurses should work with families to develop realistic compromises. For the thousands of families birthing newborns every year, this is an important pursuit with far-reaching implications for infants and the adults they will become.

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PART II: A SYSTEMATIC QUALITATIVE META-SYNTHESIS OF CAREGIVER-INFANT BED-SHARING EXPERIENCES

Part II was submitted by Marissa G. Bunch, Hillary Fouts, Sadie Hutson, and Kathryn Newnam to *The American Journal of Nursing*. Marissa Bunch is the primary author and conceptualized and planned the article. Sadie Hutson, Kathryn Newnam, and Hilary Fouts reviewed search strategies and the search audit, blind coded all data, met and discussed all coding and results, and extensively edited and provided comments on the final draft.

Abstract

Aims: To report the results of a qualitative meta-synthesis describing caregiver-infant bed-sharing experiences.

Design: Systematic qualitative meta-synthesis.

Data sources: Pubmed, CINAHL, and Scopus were searched through December 2019 for qualitative articles in English using these key words: bed-sharing, co-sleeping, reason, decision, experience, perception, perspective, knowledge, view, practice, sleeping arrangement, and culture.

Review methods: Seventeen articles met the inclusion criteria. Each article was reviewed using the Critical Appraisal Skills Programme checklist. The research team used thematic analysis to synthesize results.

Results: Caregivers described their experiences bed-sharing in terms of responsiveness, practicality, and interpersonal negotiations. Caregivers reported that bed-sharing allowed for immediate emotional responsiveness to their infant. They also felt that their baby was safer when bed-sharing and noted an instinct to keep their baby close. Caregivers said that bed-sharing was a practical solution for ensuring the infant's sleep, breastfeeding, and for addressing contextual constraints. Finally, caregivers discussed interpersonal negotiations around bed-sharing, including the influence of partners and tradition. Caregivers frequently sought others to confirm their practices.

Conclusion: Caregivers emphasized emotional responsiveness, sleep, and safety as the main themes present in their bed-sharing experiences. Caregivers were aware of safe sleep guidelines but considered other factors more important to their bed-sharing experience.

Impact: Health care providers must understand the emotional and practical difficulties of night-time infant caregiving. Nurses should consider including safe bed-sharing information in advice to new parents. Providers should advocate for family-centric policies like paid parental leave and encourage further inquiry into caregiver-infant bed-sharing experiences among diverse groups.

Key words: systematic review, qualitative meta-synthesis, thematic analysis, bed-sharing, experience, caregiver, infant, nursing, parenting

Introduction

Worldwide, 22,000 infants die suddenly and unexpectantly during sleep each year (Shapiro-Mendoza et al., 2018). Epidemiologic studies have revealed several major risk factors for infant sleep-related death which have led to declines in sudden unexpected infant death (SUID). For example, the "back to sleep" campaign resulted in a 44.6% drop in SUID in the US (Lambert et al., 2018). Since 2000, there have been slower decreases in SUID rates, prompting wide-reaching safe sleep campaigns in an effort to break the plateau (Lambert et al., 2018). Recent death reviews showed that a large percentage of infant sleep-related deaths occurred when infants were sharing a bed with a caregiver, prompting public health officials in various countries to include anti-bed-sharing messages in safe sleep campaigns.

There are many reasons that anti-bed-sharing messages may not work to decrease infant death rates. Studies have shown that caregiver-infant bed-sharing is still prevalent despite public health messages about risks (Bombard et al., 2018; Colson et al., 2013; Mileva-Seitz et al., 2017). In addition, it is not clear whether bed-sharing is independently dangerous in the absence of other risk factors; some scholars believe bed-sharing may be protective for infants (Ball & Russell, 2014; McKenna, 2012). In some countries with high rates of bed-sharing, sleep-related infant death rates were low (i.e., Singapore) (Gettler & McKenna, 2010). In fact, most sleep-related infant deaths now occur within groups living in relative poverty rather than within groups with high bed-sharing rates, which suggests that it is the particular context of sleep that determines whether bed-sharing is protective or dangerous (Bartick & Tomori, 2019).

Background

Bed-sharing might be beneficial for infants for many reasons. Anthropologists have provided strong evidence that infants evolved sharing a sleep surface with their mother, therefore

adapted to sleeping within close contact with an attuned adult caregiver (McKenna et al., 2007). In fact, Ball et al. (2016) found that bed-sharing mothers breastfeed for longer durations than mothers sleeping separately from their infants and close caregiver-infant contact has been correlated with improved stress regulation (Beijers et al., 2013). Ball (2006) has shown that breastfeeding mothers and their infants sleep in a particular orientation which ensures on-demand breastfeeding and prompt response to infant cues. Mileva-Seitz et al.'s (2017) research suggested that bed-sharing infants had more secure attachment scores than infants who sleep separately from caregivers (Mileva-Seitz et al., 2017).

There has not been enough emphasis on understanding why and how caregivers from particular regions share a bed with their infants. Bed-sharing decisions are cultural, personal, and practices vary by geographic region. Some contexts are much more dangerous than others; infants are more likely to die during sleep when placed prone or on soft surfaces, exposed to second-hand smoke, or when sleeping with a drug or alcohol-impaired caregiver (Blair et al., 2014; Carpenter et al., 2013). The emphasis may need to shift from blanket recommendations against all bed-sharing toward a recognition that bed-sharing may be safe in some situations, but dangerous when practiced incorrectly.

Some caregivers feel that bed-sharing is instinctual, making it difficult for them to follow safe sleep guidelines (Barry, 2019). Caregivers who shared a bed with their infant often expressed the feeling that sleeping separately from their baby felt unsafe (Culver, 2008). Some caregivers even feel they have saved their infant's life by bed-sharing (McKenna & Volpe, 2007). A few scholars point out that bed-sharing may be protective in certain situations and parents may be responding to an instinctual cue to keep infants close at all times (McKenna, 2012). Others emphasize the necessity of bed-sharing for sleep when mothers are breastfeeding

all throughout the night (Ball et al., 2016). Regardless, the caregiver perspective is absent in epidemiologic studies, which has led to public health campaigns that ignore the nuances inherent in caregiver-infant sleep interactions. The concern for infant safety must be balanced against the reality of caregiver night-time caregiving and an overwhelming pull to keep the baby close that some caregivers experience.

While humans are highly adaptable to environmental variation, it is becoming clearer that experiences in early childhood can affect nearly every aspect of later health (Felitti et al., 1998). Stakeholders charged with designing interventions to decrease infant sleep-related death must consider caregiver experiences and the large body of evidence linking optimal infant socioemotional outcomes with caregiver-infant proximity and breastfeeding (Gunnar & Fisher, 2006). To our knowledge, there are no meta-syntheses on caregiver experiences of bed-sharing with infants. As such, we synthesize the qualitative data on caregiver-infant bed-sharing experiences in order to elucidate the best ways to reduce infant sleep-related death while also optimizing infant and caregiver holistic health in a sustainable way.

The review

Aim

The aim of this qualitative systematic meta-synthesis is to describe the experiences of caregivers who have shared a bed with an infant. The specific research question is: What is the experience of caregivers sharing a bed with an infant?

Design

This qualitative systematic meta-synthesis was reported using the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework and results were analyzed using thematic synthesis (Thomas and Harden, 2008; Tong et al., 2012).

Each step of the search was documented in a detailed audit trail and checked by two other authors (Figure A.2). The codebook is included in Appendix B.

Search methods

Pubmed, CINAHL, and Scopus were searched through December 2019 for primary qualitative articles in English without date restriction using the following key words: bed-sharing, co-sleeping, reason, decision, experience, perception, perspective, knowledge, view, practice, sleeping arrangement, and culture. Reference lists of selected articles were examined for additional articles meeting the inclusion criteria. Articles were excluded if the population primarily included children over 12 months of age, only included quantitative data, or did not discuss caregiver-infant bed-sharing. A flow diagram of the search process is included in Figure A.2. Seventeen studies met the inclusion criteria. Article summaries, including methodology, sample characteristics, data analysis, and primary aims are included in Table A.2.

Quality appraisal

Each article was examined for quality using the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (Table A.3). All but one study was rated as high quality by the research team. This study was retained for the final analysis because it was the only study from the Appalachian US and the only ethnography, thus deemed to provide value despite its limitations (Abbott, 1992). Most studies did not adequately address researcher-participant relationships or data analysis in detail. No studies were eliminated based on quality review.

Data abstraction

Each article was read in full by the primary author and data was abstracted into Table A.1. The results section of each article was copied verbatim from the primary article into Dedoose (2020) for analysis (Thomas & Harden, 2008).

Synthesis

The data were synthesized using the process for qualitative meta-synthesis described by Thomas and Harden (2008). First, all article findings were read in full to provide a comprehensive understanding of the data. Second, the primary author performed line-by-line coding of all qualitative results in Dedoose (**2020**), remaining close to the data. Next, the primary author reviewed all initial codes, collapsed similar codes, renamed codes to give a more precise overall description, and re-read all results to ensure consistent coding. At this stage, the codes were shared with the full research team for review and revision. The research team reviewed the codes and discussion among the four members ensued, resulting in minor changes to the coding schema. Finally, analytical codes were developed to extend the synthesis past the original studies. After the coding schema was finalized, each article was blind coded by two researchers and disagreements were discussed until all team members met 100% agreement.

Results

The research team found three main themes associated with caregiver-infant bed-sharing experiences: responsiveness, practicality, and interpersonal interaction. The responsiveness theme was divided into three sub-themes: emotion, safety, and instinct. The practicality theme was divided into four sub-themes: sleep, breastfeeding, context, and adjusting to reality. The interpersonal interaction theme was divided into three sub-themes: partner interaction, seeking support, and tradition. These themes will be discussed in order of their predominance in the results. Definitions for each code and illustrative quotations for each theme are included in Appendices B and C.

Responsiveness

Responsiveness was defined as "the quality of reacting quickly and positively with interest and enthusiasm" (Oxford University Press, 2019) and was the most prominent theme across all the articles. The caregivers were highly concerned about their ability to immediately respond to their infant's cues and felt that bed-sharing was the only way to effectively respond to these cues. Caregivers relayed that the physical contact afforded by bed-sharing was necessary for the responsiveness they sought.

Emotion

The most prevalent sub-theme of responsiveness was emotion. Caregivers repeatedly spoke of their need to be in physical contact with their infant throughout the night to ensure their own psychological peace as well as the perceived emotional needs of the infant for love, comfort, and bonding (Ball, Hooker, & Kelly, 2000; Chianese et al., 2009; McKenna & Volpe, 2007). Parents talked about experiencing anxiety if they were not in direct contact with their infant throughout the night. This included worry about their infant getting too cold or even dying alone (Ball, 2002; Culver, 2008). Caregivers indicated that the only way they could soothe their own worry was to bring the baby into bed (McKenna & Volpe, 2007). Many caregivers stated that their bed-sharing arrangement was purposefully designed to produce a securely attached, socio-emotionally healthy adult (Culver, 2008). One mother said, "I credit co-sleeping with his increasing ability to handle new things, because I believe it fosters the kind of independence only feeling secure can give. I believe that babies and children left alone too much can learn to present an independent nature, but it is one based on insecurity and bravado, and leads to an insecure and needy adult" (McKenna & Volpe, 2007). They also spoke of bed-sharing in poetic ways, saying things like, "It is just the time, you know, she smells her best... she just smells like baby

products, and she's snoozy and cuddly. And she will like play with my hair or you know look at my bracelet or you know talk to me...snuggle in and it is just the best" (Culver, 2008).

Caregivers said they could not tolerate the cries of their infants and used bed-sharing as a means to eliminate infant night-time crying (Culver, 2008; Jones et al., 2017). Some parents began bed-sharing in response to unexpected infant crying at night, while others began bed-sharing to prevent crying (Bailey, 2016), Some caregivers believed this immediate responsiveness or pre-emptive method of dealing with infant fussiness would lead to a secure adult who would be capable of healthy, stable relationships (Culver, 2008). While some directly referred to attachment parenting, it was more common for them to discuss secure attachment without reference to attachment parenting directly (Culver, 2008; McKenna & Volpe, 2007).

For working caregivers, bed-sharing provided a means to ameliorate guilt from being separated from their infant throughout the day (Ball, 2002; Culver, 2008). Many justified this loss of time through the idea that they would be in close contact with their infant all night long, bonding and spending time together during sleep. Without this, they said they would feel overwhelmingly guilty and distressed about the little contact they had with their infants every day (Culver, 2008).

Safety

Parents talked about a deep sense that their infant was safer in physical contact with them during sleep (Appendix C). Caregivers were more likely to share a bed with their infants when the infant had a medical condition, including acute illness. In some cases, even if caregivers intended to sleep separately from their infants, they described greater difficulty tolerating separation if they were worried about an illness (Caraballo et al., 2016). Several caregivers brought infants into their bed when they were ill or if they had a difficult start, as with infants

who had stayed in the neonatal intensive care unit (Culver, 2008). They reported feeling that they needed to be directly in contact with their infant to respond immediately to their needs. Caregivers even relayed stories where they felt they had saved their infant's life (Bailey, 2016; McKenna & Volpe, 2007). Some said they could not sleep until they brought the baby to bed because of their fear that their baby would stop breathing or choke during sleep (McKenna & Volpe, 2007; Joyner et al., 2010). There were many caregivers who instinctively felt that sleeping in bed with their baby would best protect their baby from death (Caraballo et al., 2016; Hooker, Ball, & Kelly, 2001).

Instinct

Many caregivers specifically referred to "instinct" when they talked about sharing a bed with their infant (Appendix C). Rather than describing their reasoning in detail, some simply said it was the "natural" or "instinctual" thing to do and that is all they needed to feel confident it was the right decision (Ball, Hooker, & Kelly, 1999; Dodd & Jackiewicz, 2015; Jones et al., 2017; McKenna & Volpe, 2007). One participant referred to a "deep sense of knowing that mothers and babies belong together – why should it be different at night?" (McKenna & Volpe, 2007) and another admonished other caregivers, explaining that they should trust their instincts (Jones et al., 2017).

Practicality

Practicality was defined as "the quality of being effective, useful, or suitable for a particular purpose or situation" (Macmillan Dictionary, 2020). The practical purposes or situations for bed-sharing included breastfeeding, sleep, and other contextual situations, including a need to adjust to the reality of caring for an infant during the night.

Sleep

Other than the emotional responsiveness category, caregivers most often discussed the need for sleep when describing their bed-sharing experience (Appendix C). They found that bed-sharing allowed better quality sleep for themselves and their infant (Dodd & Jackiewicz, 2015; Joyner, et al., 2010). Many relayed that they were severely sleep deprived before bringing their baby into bed; some said the marital relationship actually improved with bed-sharing because of better sleep quality (Dodd & Jackiewicz, 2015). One mother said she "felt that I was barely functioning for the first six weeks. I was so tired, and in desperation I kept the baby in bed with me after a feed" (Hooker, Ball, & Kelly, 2001). This theme overlapped with several others for obvious reasons: many caregivers and infants slept better together because the situation allowed for immediate response to infant cries, easy breastfeeding, and the sense that the baby was physically safe, allowing for peaceful rest for worried caregivers.

Caregivers reported that infants had better sleep quality and longer sleep duration while bed-sharing (Chianese et al., 2009). Breastfeeding mothers talked about the convenience of bed-sharing; many talked about how they don't need to fully wake up to feed the baby (Bailey, 2016; Culver, 2008). Some parents didn't feel they had a choice but to bed-share in order to function during the day. One mother said she "was starting to resent her [baby] because she wanted to be by me, and I wanted her to be where she was 'supposed to be'...in her cold crib" (Culver, 2008). If it was not sleep deprivation for themselves, it was a fear of sleep deprivation for their partner that led caregivers to share a bed with their infants. Caregivers who had to work or drive during the day needed good sleep to remain safe, so they would do anything to keep peace at night (Culver, 2008; Shimizu et al., 2014). Several people said they didn't feel there was any decision-

making at all; they felt they had no choice but to eventually fall asleep in bed with their baby to get rest (Culver, 2008).

Context

For many, bed-sharing occurred due to specific contextual factors. These included marital status changes, environmental factors (neighborhood threats, lack of resources), and special medical circumstances (Appendix C). Although this theme was less common overall than those related to emotion or safety (although these clearly overlap in some cases), it was the fourth most prevalent category in this study. Parents talked about bringing infants to bed after a divorce (Abbott, 1992; Culver, 2008); one mother talked about her perceived ability to "save" her daughter psychologically from her father's abusive behavior through the closeness they experienced through bed-sharing (McKenna & Volpe, 2007). A few mothers said they bed-shared initially because their baby was born pre-term and they had not purchased a bassinet yet (Tully, Holditch-Davis, & Brandon, 2015). Others noted that they didn't have the space or money to obtain a crib (Dodd & Jackiewicz, 2015; Hooker, Ball, & Kelly, 2001; Joyner et al., 2010). A family with children who were deaf discussed how relieved they were to bring their infants to bed since touch and visual input was so important to these babies (McKenna & Volpe, 2007). There were several families with unique factors that impacted their decision to bed-share.

Adjusting to reality

Many families did not choose to bed-share until they experienced the reality of caring for an infant at night. Thus, they were not adequately preparing to safely share a bed with their baby but were reactively bed-sharing despite their initial desire to comply with professional recommendations (Bailey, 2016; Culver, 2008). Several caregivers expressed surprise at how difficult infant caregiving at night was compared to their expectations; many did not realize how

little sleep they would get in the initial months postpartum (Hooker, Ball, & Kelly, 2001). Despite owning expensive cribs and bassinets, caregivers repeatedly abandoned these devices to deal with the reality they felt no one told them about (Culver, 2008). In this analysis, it was most common that families owned a crib or other separate sleep space for their infant but decided not to use it because of other reasons.

Interpersonal negotiation

Interpersonal negotiation was defined as "the ways individuals dealt with the real or perceived opinions of other people (individuals or groups) about their bed-sharing behavior." This theme included sub-themes of partner conflict, tradition, seeking support, and concealment.

Partner considerations

The most prominent theme in this section was partner considerations. The process of discussing night-time caregiving arrangements with partners seemed to align closely with cultural conventions; in one article, participants who identified as Aboriginal found it amusing that they might ask their male partners about the baby's sleep arrangements (Dodd & Jackiewicz, 2015). They said, "if fathers were disturbed by the baby being in the same bed, they would simply sleep on another mattress or in another room if that was available" (Dodd & Jackiewicz, 2015). One woman discussed how her partner was horrified when she suggested they sleep separately from their baby; he was from Mexico and believed sleeping separately from the infant could be equated with child neglect (Culver, 2008). Many couples did not agree about the best place for the baby to sleep. In these cases, the most predominant resolution was for the mother to sleep with the baby while telling the father to sleep elsewhere if he was uncomfortable (Abbott, 1992; Hooker et al., 2001). Couples experienced conflict about their ascribed gender roles; this

was most apparent in a study out of Japan, where mothers described balancing traditional cultural ideals with modern realities (Shimizu et al., 2014).

Tradition

Many participants cited familial or cultural tradition as part of their bed-sharing experience. In some cultures, sleeping separately from the infant was viewed as bad luck, resulting in infant illness or even as a reason for sudden infant death syndrome (Abel et al., 2001). In other cultures, the tradition of close proximity (while awake or asleep) reinforced the idea that children were central to the family and came before parental desires (Culver, 2008). Participants usually ranked cultural beliefs as much more important than advice from health care providers (Dodd & Jackiewicz, 2015; Gaydos et al., 2015; McKenna & Volpe, 2007). Likewise, individuals were more likely to adhere to practices that their close family members upheld and were reassured by the positive outcomes they experienced (Bailey, 2016; Culver, 2008). It was very rare for participants to disclose that advice from medical professionals changed their minds about infant sleep arrangements; they were much more likely to avoid the topic or actively hide their practices when they conflicted with professional recommendations.

Seeking support

For those who shared a bed with their baby in a culture that did not openly support the practice, finding support from other families who were bed-sharing was important to allay their own self-doubts (Bailey, 2016; Culver, 2008). Instead of changing their behavior after speaking with people who disapproved of the practice, they sought out others who would tell them they were doing the right thing. Some found this support in local groups whereas others went to the online community to get support. One mother used the professional literature to find support for bed-sharing (Culver, 2008). When some caregivers turned to family and friends for support, they

found disapproval instead (Culver, 2008). In the studies reviewed here, these caregivers began to conceal their practices or avoid discussion while finding support for bed-sharing elsewhere rather than taking the advice of the disapproving family members (Bailey, 2016; Culver, 2008). Many caregivers found positive support for bed-sharing within breastfeeding groups and among other parents their same age (Culver, 2008).

Concealment

Caregivers purposefully avoided or actively concealed their bed-sharing practices when they knew they were going to confront disapproval (Chianese et al., 2009). When caregivers discussed concealing their practices, they referred to hiding from health care providers (pediatricians and maternal/child nurses), relatives, and friends who were openly against bed-sharing (Chianese et al., 2009; Hooker et al., 2001). One participant said, "I would take it in and listen, but it would go in one ear and it's going right out the other because I'm still going to sleep with my baby the way I sleep with her" (Chianese et al., 2009). A few mothers said they set up their cribs in accordance with guidelines distributed by home visit nurses even though their baby never slept there (Bailey, 2016). Others just avoided talking about infant sleep unless they knew the person was sympathetic to their bed-sharing practices (Bailey, 2016).

Discussion

If we are to support families in parenting decisions, we must listen to their struggles and experiences. This review has highlighted the difficulties inherent in giving widespread anti-bed-sharing recommendations to families who cannot seem to implement those recommendations into their everyday lives. By far, in the analysis, caregivers discussed emotional responsiveness as the primary factor present in their experiences sharing a bed with their infant. Attachment theory (Bowlby, 1982) centers around the caregiver instinct to maintain proximity and

immediate responsiveness to the infant as an adaptation to ensure infant survival. It is useful to consider that caregiver-infant bed-sharing may be more deeply ingrained in human instinct than is currently acknowledged in western industrialized societies. For many caregivers in these studies, the drive to keep infants safe and close was strong and was no different during the night.

No caregiver reported being unaware of safe sleep recommendations; rather, they shared a bed with their infant despite these recommendations. Most families believe that death only happens when there are other major risk factors present. Instances of infant death in prepared environments with non-smoking, non-impaired breastfeeding mothers need to be publicly discussed to convey that this occurs. If caregivers cannot safely bed-share in any situation, this needs to be clear in messaging. In fact, the professional literature also suggests that these infant deaths do not occur unless multiple risk factors are present (Blair et al., 2014).

The practical considerations associated with breastfeeding, sleep, and contextual barriers to infant sleep location are not fully considered when widespread anti-bed-sharing messages are adopted. It is extremely difficult for breastfeeding mothers not to fall asleep with babies; in fact, it is difficult for any parent to protect against ever falling asleep with their baby in the early months of sleep deprivation. In addition, there are numerous unique individual contextual nuances that lead to bed-sharing between infants and caregivers. Often these practical considerations interact with emotional responses to create a powerful drive to bring the baby to bed. Health care providers must understand these difficulties when counseling families and include safe bed-sharing information in their advice. Since accidental bed-sharing is likely to occur, all families should ensure the adult bed is the safest it can be if this happens.

Health care providers should be aware that caregivers may lie about their sleeping arrangements. Otherwise, providers may miss the opportunity to discuss ways to make bed-

sharing the safest it can be when caregivers are resolved to continue bed-sharing. Caregivers indicate that they give answers they think the provider wants to hear in order to avoid uncomfortable conversations and admonishments. Providers may get more honest answers and develop better rapport with families by portraying a non-judgmental, informed stance on the bed-sharing issue. Just like providers should discuss other risky health behaviors in a neutral, understanding manner, they are likely to get better outcomes if they discuss bed-sharing in this same way.

Finally, it is important to acknowledge the effect infant sleep decisions have on interpersonal interaction in the postpartum period. Families negotiate conflicts with their partners and balance family and cultural traditions with their desire to receive positive support by seeking out others who hold their same viewpoints. Today with global connectedness through the internet, families can find support for anything. Health care providers need to understand that this often trumps their own advice and work within this knowledge.

Limitations

This review used a robust methodological approach, but also has several limitations. The most apparent limitation is the difficulty in thematically synthesizing concepts that were developed among particular samples of individuals. For example, several of the articles involved participants from various cultural groups within different countries, so it is problematic to collapse the data together into common themes. However, these samples are fully described in Table A.1 for the reader's consideration.

Quality appraisal of these articles showed that overall, details of data analysis were lacking in the reporting of qualitative studies (Table A.3). It was rare for researchers to discuss researcher-participant relationships, so it is not possible to fully understand how this may have

affected results. Furthermore, each article's aims were different; some focused on the bed-sharing experience while others discussed bed-sharing in the context of wider infant caregiving. These differing aims may have altered the way participants participated or which facets of experience they emphasized. Despite these limitations, articles were overall of good quality and all were included in the review in order to preserve as much data as possible.

While these results cannot be generalized to all families, they can add to the knowledge health care providers bring into each encounter with caregivers of infants. The wider the scope of knowledge that is available about caregiver-infant bed-sharing experience, the more generalizable the findings will be; researchers must continue to explore caregiver experiences in various regions of the world to provide well-rounded pictures of family caregiving. The qualitative articles included in this meta-synthesis were not meant to be generalizable; rather, they are meant to highlight the experiences of certain groups of caregivers. Likewise, in this meta-synthesis we have attempted to combine these results into a digestible form suitable to present to practitioners, researchers, and policy makers, while also acknowledging that there are flaws in adapting themes across studies on particular groups of people. However, we believe it is still necessary to attempt to provide some summary of qualitative research in order to apply results to practice.

Conclusion

The results of this meta-synthesis have implications for health care practice, research, and policy. Health care providers must understand the experiences of families when giving health recommendations. Considering the enormous barriers some caregivers face when it comes to separate infant sleep, health care providers can tailor their advice depending on the individual circumstances of each family. For some, it may be contextual factors like finding access to safer

housing or financial support for heat. Still others will refuse health care advice, while being open to sympathetic professionals who are willing to discuss safe bed-sharing arrangements. Previous studies and reviews of infant bed-sharing decisions have highlighted breastfeeding and practicality as a primary factor, but this meta-synthesis focusing on caregiver experiences has shown that emotional responsiveness outweighed all other themes. This is especially significant considering that emotional responsiveness is one of the primary concepts in infant attachment and bed-sharing has been suggested as one strategy to enhance caregiver responsiveness and attachment security. Further research is needed to understand the relationship between infant night-time caregiving and attachment.

All issues of parental decision-making and negotiating the first year of life should include at least a brief discussion of parental leave policy. If parents are required to return to work while infants are still enormously dependent and emotionally vulnerable, there will be continued issues with guilt, stress, and the inability to make otherwise optimal decisions for young families. Women who must return to work early are less likely to continue breastfeeding, placing the infant at physical and emotional risk. Infants need proximate, responsive and consistent care in the first year of life to experience the healthiest outcomes. This cannot be fully addressed without liberal parental leave policies in all countries.

This meta-synthesis demonstrates the importance of asking families about their experiences. These experiences vary by region and are highly personal and variable; thus, researchers should continue to explore bed-sharing in various regions. There is little information available about the experience of caregiver-infant bed-sharing in developing countries and amongst marginalized groups in the US. For example, there is little information about bed-sharing experiences among Native Americans, Appalachian Americans, or Alaskan natives.

Researchers should seek to work collaboratively with investigators from various disciplines to advance the debate about caregiver-infant bed-sharing. It is likely that the solution will be more complex than we would like, requiring much more complex policy changes rather than just changing one aspect of the infant sleep context in an attempt to decrease the infant death rate.

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PART III: A NARRATIVE ANALYSIS OF APPALACHIAN CAREGIVER EXPERIENCES BED-SHARING WITH THEIR INFANTS

This chapter will be submitted for publication by Marissa Bunch, Sadie Hutson, Kathryn Newnam, Hillary Fouts, and Joel Anderson. Marissa Bunch is the primary author and Principal Investigator and conceptualized and planned the article with close supervision by faculty advisor, Sadie Hutson. Kathryn Newnam, Hillary Fouts, and Joel Anderson reviewed analyses and assisted with final manuscript edits and approval.

Abstract

While there is some support for the benefits of bed-sharing, the dominant discourse in the U.S. concerns the association of bed-sharing with infant suffocation. This has created a complicated situation for caregivers who intentionally or unintentionally bed-share with their infant. Caregivers share a bed with their infants for many reasons and sleep decisions are often influenced by context. Providers must understand each family's unique sleep situation to make effective recommendations. However, there are no studies about caregiver bed-sharing in Southern or South-Central Appalachia. Thus, this article presents the results of a narrative analysis of Appalachian caregivers' experiences bed-sharing with their infants in the past five years. Unstructured interviews were conducted with 12 primary caregivers from Southern and South-Central Appalachian counties Findings revealed that stories were varied and highlighted that health care providers should tailor their recommendations to each particular situation. If providers do not give safe bed-sharing education, caregivers may inadvertently place their infants in dangerous situations and conceal their sleep arrangements.

Introduction

Safe sleep guidelines from the American Academy of Pediatrics (AAP) recommend room-sharing but no bed-sharing for infants under 12 months of age (AAP Task Force on Sudden Infant Death Syndrome [SIDS], 2016). However, there is still debate about whether infant deaths while bed-sharing occur in the absence of major risk factors (i.e., exposure to cigarette smoke or sleep with an impaired caregiver). In fact, some scholars argue that bed-sharing may be protective for infants (Blair et al., 2014; McKenna, 2012). Many caregivers share a bed with their infant for various reasons, even when they are aware of the guidelines that strongly recommend against bed-sharing (Joyner et al., 2010; McKenna & Volpe, 2007). Furthermore, in some cultures, bed-sharing is widespread and there is little stigma against the practice in comparison with the U.S. (McKenna et al., 2007; Mileva-Seitz et al., 2017). There are still no official safe bed-sharing recommendations for providers to give to bed-sharing families. Many providers do not discuss safe bed-sharing practices with families who choose to bed-share and some caregivers conceal their bed-sharing practices from providers (Bailey, 2016; Chianese et al., 2009).

The AAP's safe sleep recommendations have inspired widespread public health campaigns about the "ABCs" of safe sleep: Alone, on the Back, and in a Crib (Tennessee Commission on Youth and Families, 2018). Health care providers are instructed to ask about safe sleep at infant well-child visits and to notify families of the risk of suffocation or SIDS when they admit to bed-sharing. Families are aware of these policies because the messaging is widespread; safe sleep messages are on billboards, buses, clinics, and changing tables in public bathrooms. Some caregivers have reported lying about their infant's sleep location to avoid confrontation or shaming (Chianese et al., 2009). In many cases, these caregivers explained that

they did not know how to manage the night-time caregiving of an infant without bed-sharing (Ball, 2002; Culver, 2008).

Background

Families face many challenges with infant night-time caregiving, especially during the first few months of life. In several studies, breastfeeding mothers described sleep deprivation and milk supply issues when they tried to sleep separately from their infants (Ball, 2002; McKenna & Volpe, 2007). Other caregivers reported that the anxiety they experienced when sleeping apart from their infant was so strong that they found it difficult to sleep (Hooker et al., 2001). Some caregivers reported an intuitive sense that the baby was safer when bed-sharing as compared with sleeping on a separate surface, even when they were in the same room (Gaydos et al., 2015). Some caregivers reported bringing their baby to bed specifically because of the fear of SIDS; they felt they could monitor the baby's breathing more effectively when they were touching throughout the night (Abel et al., 2001).

Caregiver-infant bed-sharing may be beneficial for infants. Studies of mother-infant separation after birth have suggested that any separation might be stressful (Gunnar & Quevedo, 2007). Other studies have strongly supported a link between breastfeeding and bed-sharing. In Ball et al.'s (2016) study, mothers who shared a bed with their infant and breastfed throughout the night were more likely to continue exclusive breastfeeding for an extended period of time.

Even though there has been some support for the benefits of bed-sharing, the dominant discourse in the U.S. has concerned the association of bed-sharing with infant suffocation. Admittedly, these cases are tragic and stand out in the minds of providers. However, the literature on infant death and bed-sharing is complex. Infant bed-sharing deaths have been associated with other risk factors like sleeping on a recliner or sofa or sleeping with an impaired

caregiver (Carpenter et al., 2013). Moreover, most studies have not effectively controlled for drug and alcohol use by the caregiver and some have even combined bed-sharing caregivers with those who slept on a couch or sofa (an environment known to be extremely dangerous for infants) (Blair et al., 2014; Vennemann et al., 2012). Caregivers often decide the risks do not apply to them or that benefits outweigh risks (McKenna & Volpe, 2007; Volpe et al., 2013). In several studies, caregivers reported that health care providers' recommendations did not cause them to change their bed-sharing practices (Chianese et al., 2009; Hooker et al., 2001). Thus, it is worth exploring whether this is true for other populations and whether it is time to give some families information on safe bed-sharing.

More studies are needed to explore caregiver experiences of bed-sharing in various contexts. Southern and South-Central Appalachia have infant mortality rates 16% higher than the rest of the U. S.(PDA, Inc., The Cecil G. Sheps Center for Health Services Research, & Appalachian Regional Commission, 2017). Despite this higher infant mortality rate, there are no studies on infant bed-sharing practices in this region. This infant mortality rate includes rates of Sudden Unexpected Infant Death which include bed-sharing deaths in the U.S. Therefore, the purpose of this study was to understand the experiences of caregivers from Southern-Central Appalachia who shared a bed with an infant within the past five years using narrative inquiry.

Methods

The central unit of analysis in narrative inquiry is experience as represented through story (Clandinin & Connelly, 2000). Narrative inquiry was chosen for this study for several reasons. Caregiver-infant bed-sharing is experiential, there have been no narrative analyses examining bed-sharing, and the Appalachian region of the U.S. has a strong storytelling history. In narrative inquiry, each participant's story is considered in its unique and intact form. Therefore, data

saturation and reduction across participants is not the primary goal (Clandinin, 2006). Dewey's theory of experience as an interplay between continuity, interaction, and situation was used to guide this narrative inquiry (Clandinin & Rosiek, 2007). Each of these facets was analyzed for each narrative. In this study, "narrative" refers to one entire interview transcript and "story" refers to sub-units of the transcript with apparent beginnings and endings.

This study was approved by the Institutional Review Board at the University of Tennessee-Knoxville (UTK IRB-19-05542-XP). A purposive sampling method was used to recruit participants who met the following inclusion criteria: over age 19 years; identified as the primary night-time caregiver for an infant in the past five years; regularly shared a bed with their infant when the infant was less than 12 months of age; from a Southern or South Central Appalachian county (Appalachian Regional Commission, 2009); able to read, speak, and write in English; and the bed-sharing infant had to be over 12 months of age at the time of interview. Regular bed-sharing was defined as at least 4 hours every night, 5 days every week for 1 month of the infant's first 12 months of life.

The Principal Investigator (PI) posted a digital flyer (Figure A.3) and a link to an anonymous online survey (Appendix D) in co-sleeping and Appalachian Facebook groups to recruit eligible participants. Prospective participants emailed the PI to set up an in-person interview if they qualified for the study and wanted to participate. At the in-person interviews, the PI reviewed the written informed consent for interviewing, audio recording, and follow-up emails with each participant and each participant gave written informed consent. Directly before recording, the PI gave each participant a safe sleep handout (Figure A.4) along with $30. The average interview time was 53 minutes (range 20 minutes to 2.25 hours) and interviews were conducted in February 2020.

The central unit of analysis in narrative inquiry is experience as represented in stories. Narrative inquiry involves analyzing stories in their unique and intact form and narrative inquirers do not seek to reach data saturation or conduct thematic analysis across participants. Thus, determination of appropriate sample size often depends on availability of resources, space for analysis and reporting in published studies, and the research question. For this study, the PI conducted a review of the literature using "parenting," "nursing," and "narrative inquiry" as search terms. Out of 27 relevant studies, the average sample size was 16 participants, with a range of 1 - 81. Most studies included 10 or fewer participants. Almost all of the studies used thematic analysis to present data. When authors presented data as intact stories, sample sizes were much smaller (e.g., Adkins & Doheny, 2017). Therefore, the goal for this study was to recruit 10 - 16 participants in order to present the uniqueness of each story in its intact form in the final report.

After beginning the recording, the PI stated, “If you want, we will start with you telling me whatever you would like about who you are,” and then, “Ok, why don’t you tell me about your bed-sharing experience.” The interview was largely non-directed and open-ended. At times, the PI prompted for certain topics that had not been discussed. These topics included negotiations with spouses, interactions with health care providers, and opinions about bed-sharing views in their community. Within one week after the interview, the PI listened to all recordings twice and made field notes. Then, the PI transcribed and anonymized all interviews. Anonymization at this stage involved replacing names with pseudonyms or deleting names and places.

Data analysis followed methods for narrative inquiry and Dewey’s theory of experience (Clandinin & Connelly, 2000). First, narratives were read in full several times to get an overall

sense of the structure, syntax, semantics, plot, and themes. Then, the PI performed the following steps in order for each narrative. First, an outline of topics and stories was created. Next, topics were separated into the dimensions of experience: continuity (past, present, future), interaction (intrapersonal and interpersonal), and situation or place. Then, the PI decided what type of plot the overall narrative represented and identified the main characters. Finally, syntax and semantics were noted and meanings deduced. During initial readings of the narratives, the PI highlighted statements that summarized the overall theme of the narrative. At the end of the analysis, the PI returned to these statements and chose the one that most accurately represented the overall meaning of each narrative. Four other senior researchers also reviewed the PI's analysis methods.

Anonymization within the final article was complex because analysis did not involve generalization across participants (Saunders et al., 2014). To address this issue, the PI kept ages, careers, and other potentially identifying information masked in the re-telling of each story. Some details were changed in an attempt to preserve anonymity. The goal was to make changes that did not affect the results; however, there were times that information that might have contributed to the results had to be eliminated in favor of anonymity. The ages and genders of children in the study were masked; instead of using "he" and "she," the authors substituted the gender-neutral "they." Genders of participant partners were also masked to confer another layer of anonymity. In this study, all participants were married and referred to their partners as "husband" or "wife," but this was replaced with "partner" where applicable. For this study, the PI focused on bed-sharing and downplayed other stories that had the least effect on understanding the participant's bed-sharing experience. Admittedly, all of these choices affected the results and were not meant to diminish the importance of these details to each participant's

experience, but to protect participant anonymity, present a streamlined account, and respond to the research question. Each participant was emailed a short summary of their results and no participant objected to the summaries.

Results

The anonymous online survey designed to determine eligibility was completed by 49 individuals and viewed 492 times. The survey completion rate was 52.13%. A total of 12 participants completed the study, five from Southern and seven from South-Central Appalachian counties. These were the first 12 participants that qualified for the study and arranged in-person meetings. All participants identified Southern or South-Central Applachian counties as their home. One participant was originally from outside of Appalachia but had lived in Appalachia for five years. All other participants were born in Southern or South-Central Appalachian counties. Two participants described living in varieous other areas of the U.S. over the years. Participants were from two states and 10 counties. There were 11 females and one male, all were married, and participants included one couple. Some participants were in same-sex marriages and some had re-married after divorce from the bed-sharing child's biological caregiver. Participants' ages ranged from 26–41 years and their children were all less than 10 years old (including non-focus children). The focus children's ages ranged from 12 months to 5 years of age.

The following narratives were primarily situated in the recent past and present. All narratives included spouses and children as main characters; other main characters and references to the future will be discussed when relevant.

“Maggie:” “My job is to protect my child.”

Maggie spoke in a pressured manner, frequently stuttering in enthusiasm as she talked about her decisions as a mother. Her narrative had a Joycean plot and covered 42 topics. Main characters in her story included her parents, her sister, and other mothers. Her narrative jumped back and forth through the past, present, and future. She devoted the most time to discussion of interpersonal interaction but also spoke about intrapersonal interaction and place.

The 42 topics discussed in this narrative underscored that for Maggie, bed-sharing was about all of life. She said, “[This is] basically a study about how you’re living. ‘Cause it all ties in. Sleeping is a big part of human life and how we operate….how we choose to sleep.” Maggie said she was against bed-sharing before her pregnancy. She explained that she always thought it made sense to keep babies in their own beds so they would develop independence and to avoid the struggle to move them into their own beds. However, she quickly moved into her current enthusiasm about bed-sharing since having children.

When Maggie came home from the hospital with one of her children, she put them to sleep in a bassinet beside the bed. However, she said,

> We proceeded to not sleep for a week because they wouldn’t sleep in their bassinet. They wouldn’t sleep in their crib; they wouldn’t sleep anywhere but in my arms. And after a week, one night I felt like I was losing my mind.

She reiterated how serious this dilemma was through her repetition and short declarative statements. She said she slept better than ever after moving her baby to the bed. After that first week and until her other child was several months old, Maggie never tried to put them anywhere but her bed. Maggie was breastfeeding and felt it was both easy and natural to share a bed. While she was afraid because she had heard about the risk of suffocation, Maggie quickly decided

through her own reading that this did not apply to her because she was bed-sharing safely.

A large majority of Maggie's narrative involved other decisions she made that went against the mainstream. While she was warm and welcoming, her strong declarative statements and conviction conveyed a deep mistrust of authority. She had not vaccinated her children or established a pediatric provider and she had a home birth. Maggie thought all of her choices had been similar to her decision to share a bed with her babies because they all went against what she saw as the mainstream.

Maggie described differences in people based on neighborhood. She described moms in a neighboring city as

> more judgmental and harsh and they get cliquey and they're the middle to upper middle class, but they still have this country bumpkin kind of thing going on alongside it. So to me they're just not as friendly and accepting and kind.

Again, she widened the lens and spoke more generally rather than specifically about bed-sharing. She said she felt that people around her tended to follow authority blindly. Yet, Maggie also said she felt bed-sharing was "everybody's dirty little secret." There were several instances of contradiction in her stories. These contradictions displayed her internal conflict with different ideas. For example, she strongly suggested that every family situation was different and that parenting is a "game of guess and check" and "we're all just wingin' it! You're fakin' it 'til you make it." However, she also expressed her belief that most people accept what authorities say without enough questioning or personal reading.

Maggie used iterations of the term "research" 14 times throughout her interview. It was unclear what she meant by "research," but she did say,

> If you read everything, then you're fine. It's not like I'm picking and choosing and cherry

> picking the information that I'm reading. I'm reading stuff from everywhere because I want to know the truth. The problem is they don't have the truth documented anywhere. So I'm just, I'm doing the best I can.

Again, there was a display of contradiction as she said most people did not read enough to make decisions that go against mainstream ideas, yet she also said the truth is not documented anywhere. Her internal struggles were revealed many times through contradictory statements, as though she were still working out her position on the spot.

Maggie talked about her idea that there was a universality to bed-sharing because:

> On an animal level, we're the only species that puts our infants in different rooms than us at night, which on an animal instinct level is bad. You want to protect your young. And I think our social culture pushes us further and further away from normal animalistic things that necessarily aren't bad for us.

Again, Maggie expressed her feeling that bed-sharing was about life. For her, bed-sharing represented one issue that exemplified many things that are wrong in society today.

One night, Maggie woke to a loud thump. Her baby had fallen off the bed despite her placement of a pillow on the bed-side. Maggie said this was the last night this child slept in her bed. She "stuck them in the crib" and they slept all night almost every night after in the crib. She repeatedly talked about how different her children were; one child weaned before 12 months, while she described pushing the other child to quit nursing after a few years. One child always asked to be taken to their own room to sleep while her other child continued to sleep in her bed every night.

Maggie said she believed it was a parent's job to give their child what they needed and that every parent had access to information and had the capability to make the right decisions.

Maggie felt attacked by one provider because she refused some interventions for her child after birth. She re-enacted her rebuttal to this provider's question about the reasons for her refusals:

> My job is to protect my child. And I did plenty of research and I have plenty of knowledge about my rights and what I can and cannot do. And you have no right to ask me that question and I need you to get out of my room right now. I was like, you have seriously offended me. And honestly, you should lose your job over crap like that. You should never make anybody feel that way. You're not allowed to ask that question at all. And they were just like, "Oh my God." And they left. They were like, "well, I'm sorry." And I'm like, I don't want your apology. I don't care. I of course hadn't slept at that point either, but I was just like, get the hell out.

Maggie's story related her belief that parenting decisions lie solely with the primary dedicated caregiver and that no authority outside of that person had the right to suggest otherwise.

"Kristina:" "People don't understand this."

Kristina was a professional with a graduate degree in a health-related field. Her narrative came across like an informational text even when she relayed stories of her anger or frustration. Kristina detailed the interpersonal aspects of bed-sharing and didn't talk about the distant past or future. The main characters in her story included her parents, siblings, friends, and co-workers.

Kristina opened her narrative with a story about her father buying them a crib when he found out she was pregnant. She said, "he's kind of old school." This set the stage for her belief that bed-sharing was untraditional; as she continued, she noted how bed-sharing came naturally to her. She had both children at home in the bed and she said,

> We didn't really think about it, but we didn't really want them in another room away

> from us. A lot of people had the pack 'n' plays and all that kind of stuff and we were just both very comfortable with having them sleep next to us the whole time…we really felt it's natural and we felt like they were safe. It was easier on me because I didn't have to get up in the middle of the night to go get them.

Kristina did not take medication and gravitated toward non-traditional health care providers. Bed-sharing felt like an extension of her overall approach to life.

Kristina's story was filled with interpersonal interaction. There was the first story of her dad wanting to buy the crib, perhaps as a symbol of his commitment as a grandfather. Then there were stories about the differences in her children, discussions with co-workers, and how bed-sharing had affected her sexual life. Kristina did not feel that co-workers supported her decisions to share a bed with her children. Safe sleep messaging was rampant in her field, so it made sense that her co-workers were aware of anti-bed-sharing messaging. However, when Kristina first began talking about her co-workers, she didn't mention the risk of death. She noted their support for breastfeeding but felt the lack of support for bed-sharing was about "lack of understanding." She said:

> So I had to pump every two or three hours and I had a lot of support with that. But when it came to the bed-sharing, they didn't understand. I think if I wasn't one of their co-workers, they would have brought it up to somebody who could have taken a little more action. They were definitely not supportive, which was interesting. And I mean people were like, "Oh well that's, I don't know about that." I mean I would get these comments, because I am very open to, "Hey, we co-sleep, we do attachment parenting."

When prompted about the reasons for the lack of support for bed-sharing, Kristina explained that

she thought some people who worked with the public were afraid of liability for infant deaths associated with bed-sharing. She believed these infant deaths happened mostly among lower income individuals who were impaired with drugs or alcohol while sleeping with their baby. She talked about her surrounding area:

> You have a lot of diversity, you have a lot of different incomes, you have a lot of drug use. And you know, I think I can understand in a sense them having to come out and say, "Hey, look, we can't allow co-sleeping," because if we encourage that and some person's on drugs and they roll over and smother their kid, who's that gonna come back on? "Oh, well [this person or that person] said it would be okay." I think they drive that into them to the point where that is the mentality they have to have.

Kristina talked about researching her decisions and said,

> I do a lot of research. When I was breastfeeding, I did research. When we had to make decisions about vaccines, we did a lot of research. I love the research. I've read a lot of studies about co-sleeping and I think it just really depends on the situation.

She frequently emphasized that different situations must be considered. She discussed the irony of all the expensive baby equipment being sold to prevent infant death during sleep (oxygen sensors, monitors) when "there's a very simple solution to this. Have your kid right there." While she believed bed-sharing was safer than separate sleep for babies, she was also quick to clarify that she did not advocate what she termed "mom-shaming." She said, "I call it mom-shaming. There's no mom-shame about your sleeping arrangements." While she conveyed that bed-sharing could be a solution for many people who felt anxious about their infants at night, she also understood that situations varied.

While Kristina covered a lot of information in her narrative, she continually came back to the refrain, “it’s just a lack of understanding.” She didn’t always elaborate on what she meant, but when prompted, she could detail the reasons people have for not bed-sharing. However, she seemed to sum up all the considerations by saying “they don’t understand.”

When Kristina brought her children to a practitioner who was open to alternative practices, she was open about bed-sharing. She said this provider was supportive and the provider even revealed that she had also shared a bed with all of her children. However, Kristina remembered telling her partner, “Don’t bring it up. Don’t bring it up. If you’re asked the question, don’t bring it up” before they walked into their child’s appointment with the provider. Another provider asked about their sleeping arrangements and she told them, “that’s none of your damn business,” while she remembered another provider using a leading question: “They sleep in the crib, right?” She answered, “’Sure. You made the leading question.’ I didn’t answer, I didn’t say an answer. Either they didn’t want to know the real answer or they were legally bound by their practice to ask.”

Kristina felt that her natural approach to parenting was supported everywhere she lived except in the Southeastern U.S. While she was from the city she lived in at the time of the interview, she and her partner married in another state and had lived in several others. She said they felt supported overall, except “when we come here and we’re talking about co-sleeping and babywearing and attachment parenting, everybody is much more like, ‘Oh, I don’t understand. What is that? What are you talking about?’” While she refused to “mom-shame” and kept in mind that “it all depends,” she continued to return to her refrain, “they don’t understand this.”

“Kyle:” “It’s all about the information.”

Kyle was a stay-at-home dad and retired from the military. Kyle told an autobiographic narrative and spoke in long stretches about interactions with people in the military and school, delineating whether he felt supported in his parenting decisions or not. Kyle’s story was sequential and started with the births of his children, moved through early parenting and his military years, and progressed toward the present day and his frustrations with societal biases, including perceived biases against stay-at-home dads.

Kyle placed a focus on whether he had received support for his parenting decisions from others. It became clear that Kyle’s return to school later in life had a huge influence on him and was defined by whether he could find support from other parents. He talked about always feeling accepted by other service members. He said, “we wear green and bleed red, you know, that’s as far as our differences go.” He felt his family wasn’t judged by other service members for their choices on prolonged breastfeeding and bed-sharing because of the cultural diversity. To Kyle, the bias he felt was attributed to “the Southern Baptist, force-it-down-your throat…stereotypical people.” Kyle’s narrative featured a story about running errands one day with his child:

> This one particular time, it really set me off. I was at a store going to check out and the cashier, an older lady, had like three crosses on her, pinned on her vest and a Jesus shirt on. She was like, “Oh being Mr. Mom today?” And I about lost my shit. I’m like, “No, I’m a father, I’m parenting. He is here with me. I am not Mr. Mom. I am his dad.” And she about shit herself…I was pissed about it. Those are the type of people I run into that have the problems with how we parent. Cause it’s very noticeable that our kids have a very close connection with both of us but when I’m out with one or both of them, it’s daddy, it’s not, well mommy.

This story illustrated the "stereotypical" religious person he felt encapsulated those who judged his natural parenting style. This story conveyed Kyle's struggles with his image as a primary caregiver, his association of judgment with religion in the South, and his irritation at assumptions about gender and parenting. He expanded on some of these issues later, when he pointed out that he thought women dealt with more judgment from other females than he had ever received from other males. He said "not once has anybody ever said, 'Oh you shouldn't do that. You're a bad person,' or you know, anything in that realm. It's crazy the difference in support amongst moms and dads."

Kyle spent a lot of time talking about his work and justifying why it made more sense for him to be home with the children than his partner. As Kyle's narrative drew to a close, he reflected more on his wider thoughts about bed-sharing. When he discussed the circumstances of bed-sharing and how he and his partner prepared to share their bed safely with their babies, Kyle said,

> If you don't arm people with the actual information, how are they supposed to make an informed decision and decide if it's the best practice for them or not? It's all about the information. If you don't give somebody the correct information, you cannot make an appropriate decision for what the situation is. Regardless if it's a combat situation or if it's parenting. If you don't have the real data, it's a shit show. You're just shooting, you're just throwing darts in the dark hoping you hit something. I mean it doesn't work that way.

Kyle thought people were not given all the information about bed-sharing. He thought they needed to understand which circumstances made it dangerous so they could prepare the best way they could for their own situation. He used his military training to examine

the situation and concluded it was “all about the intelligence.”

“Laura:” “You can’t argue the benefits of the biologically normal alternative.”

Laura’s narrative had a comedic plot; it was meant to make a statement, much like stand-up comedy. The characters in Laura’s story included her parents, former bosses, medical professionals, and other mothers in her community. She spent a lot of time discussing the safety measures she implemented while bed-sharing.

Laura began with a story that got right to the point. She said,

> I was ignorant until the day they were born…then I became this huge breastfeeding advocate and I got really involved and everything and my family was all like, ‘This nut! She’s really, really crazy…she’s gonna be one of those people’…And I am.

She felt she had strong maternal instincts that led to this change. With her first child, she struggled with the postpartum blues. She tried to use the crib repeatedly until one day, she started bed-sharing:

> I exclusively breastfed and somewhere, you know, about that one- to two-week time period, I was like, I can’t let them sleep over there alone. They’re cold, they need me. I can’t keep getting up and feeding them and trying to put them back to sleep and trying to lay them back down. I’ll never sleep again in my life. Something’s gotta give.

Though her partner did not agree at first due to safety concerns, Laura was adamant. She told her partner:

> My sanity is waning. We. Need. To Do. Something. You will either live happy, sleep at night, I will take care of the baby in the bed OR I’m gonna die. It will be at the hands of sleeplessness or myself.

As she continued to share a bed with her children, Laura became a well-informed breastfeeding advocate and learned to find studies to back up her beliefs.

Laura talked about how they went from a queen to king bed to make more space for her child, installed a bed rail on her side of the bed, and removed pillows and blankets from the baby's sleep space. She also repeated several times that "neither one of us smoke or drink or use any recreational drugs. That's big for in this area." Similar to some of the other participants, she had a family friend who lost an infant to SIDS and admitted she was aware of risks. For Laura, bed-sharing deaths occurred because of particular risk factors that could be reduced. She said,

> I mean, I don't think we were designed to be miserable. I understand that they want to prevent tragedies. But there are some things you can't prevent and as long as you're as safe as possible, you can't spend your life trying to avoid things you can't prevent.

With one child, Laura lied when the provider asked if they shared a bed. However, when her other child was born, she said,

> With my first one I was really scared but my second one, I had armed myself with enough knowledge. I marched in there and I was like, "I've got all kinds of information to argue with you"….[laughing] And I do. I argue with my pediatrician about flu shots and vitamin D and co-sleeping and breastfeeding and…You can tell me whatever you want and I'm still gonna make the decisions that I think are the right decisions.

She marched into the office with confidence the same way she had marched around her community fighting for the rights of breastfeeding mothers.

Laura felt that people in her area tended to

> blindly follow what mother and grandmother tells them…or they blindly follow what the pediatrician tells them…They take it for truth and they don't even question it. Ever…they don't wanna argue…they don't want to have a hard discussion…No. I mean, I didn't like it.

Her solution to this was to increase mother-to-mother interaction so other mothers could know there were alternatives to their family practices. Laura said mothers were going to bed-share anyway so they needed to get information from someone. She admitted that there were situations that made bed-sharing too dangerous but reiterated that "you can't argue the benefits of the biologically normal alternative. You can't argue that."

"Jennifer:" "I'm out of the ordinary…I feel bad for these kids that when they're born they're ejected into this system."

Jennifer spoke a lot about her intrapersonal experience compared to other participants. Although she identified as from Appalachia, she grew up outside of the area, so she talked about the U.S. South with an outsider's perspective at times. The main characters in her story included other moms, other children, and her parents. Her narrative could be described as a forbidden love romance, with her love for her children at the center of a system that often disapproved of her actions.

Jennifer started with her desire to give her children "the least chemical-rich start that I can" and that she was a "combination of natural and not natural." She said she believed in bed-sharing, did not vaccinate, and that her children had never seen a medical provider. However, she did let them have sugar so she wasn't "one of those weird total crunchy people." She began bed-sharing with her first child without much thought; they would start in the bassinet and then Jennifer would leave them in bed because it was easier. She said, "It wasn't a conscious decision

like, ‘hey, this is what we’re going to do.’ It was kind of just, how can we get the maximum amount of sleep so that we don’t die?” Remarkably, Jennifer did not mention breastfeeding at all in her narrative. She placed most of her emphasis on her need to know that her children were safe and that they felt loved at all times. She contrasted her loving, warm parenting style with a modern U.S. tendency to obsess over infant independence.

Jennifer felt a deep sense of isolation because of her beliefs. She said she felt like an outcast because everyone around her had a certain rigid belief system that was different than her own. She used each of the following words twice throughout her narrative: “outcast,” “lonely,” and “isolated.” She presented vivid descriptions of her feelings. Toward the beginning of her narrative she said,

> They spent 9 months in the dark—warm in here [wraps arms around her abdomen] — then they come out and this world is just cold and confusing and loud and bright and— how would you feel if you couldn’t remember all of that and then you got spit out into your own bedroom and all of a sudden you wake up in the middle of the night and you’re like, what is going on? And then your mom is not anywhere to be found.

This section seemed to mirror her own feelings of being lonely, cast out, and confused about the world around her. She said,

> I don’t have any friends here…I haven’t really found my people. People are just shifty these days. And I mean, I can’t find anybody that clearly wants to be a friend, you know? So it does get a little bit lonely.

Jennifer wanted to raise her children in an environment where there was no room for doubt about the love she had for them. She went on to say,

> For me it's really simple. I want to be close to them. I want them to be close to me. They came out of my body and I don't want to just put them out into the world and be like, "well, good luck. If you need me, just cry about it." I mean that doesn't even make sense to me.

Jennifer felt that most people in her community looked at her like she was a "weirdo." She thought there was a system people followed mindlessly that included birthing babies in a hospital and vaccinating, and because she hadn't followed that system, she felt alone. While her partner disagreed with bed-sharing initially for safety concerns, she said they eventually agreed with her and that they would defend her against anything that made her question if she was mothering effectively. Jennifer told a story of how her young child once took cigarettes out of her purse and began to pretend she was smoking out in public. When Jennifer told her child to put the cigarettes away, her child said, 'Well you let us smoke at home!' This story seemed to represent how she was repeatedly put in positions where other people made her feel like she was failing as a mother. She said that an older woman standing nearby "was just one of those very like old-fashioned" ladies and that the lady was like "Oh my God!" and that she "could see her calling the cops on us." Jennifer was giving a humorous and exaggerated example of how she was misunderstood and judged by people around her, whether that be for her anti-vaccination or bed-sharing beliefs or something else entirely. Regardless, she conveyed that others did not understand the full picture.

For Jennifer, bed-sharing was one behavior of many that defined who she was as a mother. Although bed-sharing started out of desperation for sleep, it evolved into a deep-seated connection between Jennifer and her children. Bed-sharing became part of the lifestyle that she

thought made her an outcast. Jennifer didn't understand other people's parenting decisions and thought people did things without much thought. She said,

> I feel a little bit isolated from people my age because they do what people normally do….There's such a system. I feel like I'm out of the ordinary around here as far as my beliefs and it's kind of sad honestly. I get a little bit sad about it because I feel kind of bad for these kids that when they're born they're ejected into this system and it's kind of just…I don't know. I feel like people don't know any better, so they just do what they think they're supposed to do.

"Amber:" "While there are ups and downs in our journeys, no two stories are the same."

Amber was a stay-at-home mom who home-schooled her children. She began her narrative with a telling comment: "You can tell from the oils and the elderberry syrup and all, we try to approach things from a natural perspective." Amber told a coming-of-age story as she detailed how she went from a naïve to experienced parent and changed her approach along the way. She said ,"if it's not working, then let's keep figuring out what it is that we can do to change." The main characters in her narrative included breastfeeding consultants, pediatric providers, and other moms. Most of Amber's narrative was spent discussing interpersonal interaction.

Amber noted how different all of her children had been. She breastfed her oldest for a few years while her youngest weaned himself before 12 months. Her first child started sharing a bed with her because breastfeeding was difficult and Amber was getting little sleep. She said, "we were up a lot and being in survival mode as a first-time mom and doing a lot on my own because of my [partner's] career, sleeping with us was just the best option." Amber described one of her other children as very independent. She could tell they didn't want to bed-share after a

short time despite continuing to breastfeed. Yet a different child wanted to nurse constantly at night. She found herself up all night so they made the decision to sleep-train this one after a few months. She said,

> It got to the point where your tears didn't really bother me that much because we'd been up 17 times in one night. And that's not an exaggeration. Um, so, you know, it shifts with each child and this one is a happy medium between the others of wanting me and independence. So I don't think we totally screwed up. But it changes from the first time around, every whimper you jump to it quickly. And the next time, that one was naturally more patient and waited on us when they got upset and things like that. Now this one says, 'I am your monkey and this is your circus.' They are all so different. I mean, we joke all the time that we thought we had it figured out until this one came.

Amber said her children would sleep "tucked in to me." She would place a pillow at the other side of the bed when her partner was out of town for work so they wouldn't fall off the side. Many nights, they started in a bedside bassinet but ended up in the bed with her after breastfeeding. A lot of her discussion centered around her move toward natural parenting after she had become dedicated to breastfeeding, which she described as "the most unnatural natural thing you're ever going to do in your life." Her decision was not influenced by health care providers in any sense.

Amber described her evolving relationship with her pediatric providers. Amber used metaphors involving hands several times in her narrative. She described her nurse practitioner as providing a "hands-on" experience and described her partner as a "hands-on" parent. She said she wanted the nurse practitioner's "dirty hands of experience and

support." For her, nurses were the ones deep in the "dirt" of patient interaction in the hospital, thus they were better equipped to understand her point of view. Still, she said she "skirted by" and told her providers what they wanted to hear, if only to avoid unnecessary conflict. She told a short story to illustrate:

> I learned quickly that when it comes to the list of questions, within reason, when they want to know about how often they're nursing—15 minutes on each side is the magical answer. And they just say, "okay," so you know, "15 minutes on each side." I don't run a timer! I don't look at the clock! I don't know how many poopy diapers they've had today! I've got several kids. I don't have time to count that. Are you kidding?

She said she never outright lied about where her babies slept, but also "probably wasn't always 100% forthcoming."

Amber felt that the communities she had lived in had differences based on overall socioeconomic status of residents, but that she had been able to find support within each one. However, she wished finding support was easier for other parents. She said, "especially women–because I don't feel like men are as hard on each other, but I just wish that we could be and feel more supported." She used the word "support" 25 times throughout her narrative. Amber felt that what worked for one person on one day may not work for another person or on another day. Her own story exemplified how many changes one family made daily. She said, "while there are ups and downs in our journeys, no two stories are the same…whether it's my stories with my children (none of them are the same) or my story versus her story."

“Emily:” “I think there needs to be an alternative narrative.”

Emily worked in the medical field with families from multiple cultures. She presented her narrative as a persuasive essay about why she couldn’t imagine any other night-time arrangement other than bed-sharing. The main characters in her narrative included her clients, midwives, providers, and dog.

Emily thought about her child’s sleeping arrangement before pregnancy because her provider asked her about her plans. This provider came to her home for a pre-birth visit and showed her how breastfeeding mothers tend to sleep in a particular, protective “C” shape when bed-sharing. Emily felt like she made the decision to bed-share around that time. When her child came home, she briefly tried to use the bassinet by the bed, but she said, “they would not sleep not touching me…we were kind of like, this is not working. They will not stop crying. They need to nurse to sleep.” Since that day, Emily said her child never slept one night outside of Emily’s bed, although she napped in her own crib during the day. Emily placed a rolled-up towel around the baby to give them a dedicated space but that felt like separation, so she removed the towel. When the baby started rolling, she pushed the bed up to the wall to prevent falls.

For Emily, “bed-sharing goes hand in hand with breastfeeding.” She nursed her child constantly throughout the night and explained:

> I literally don’t know how I would survive if we didn’t bed-share. I would be a zombie. I feel like that’s one reason people wean at night and then that affects your supply and then you stop nursing prematurely. You had to do it for your sanity. I can’t imagine doing it any other way.

She explained that her child rarely cried because she and her partner were so responsive all the time. Emily believed immediate responsiveness in infancy would lead

to an independent, secure adult. She believed infants were dependent and needed to remain close to their parents in the first year of life for optimal development. She said,

> Babies are not meant to be independent. For months of their lives babies still think that they're the same entity as their parents. If they can't distinguish that we're not the same, I probably shouldn't be taking their other half away from them. I should be close to my baby as much as possible. Sleep training, which would be the opposite of what we're doing is very much like, 'well, I got my baby to sleep from 7:00 PM to 7:00 AM.' And I'm like, congrats. What kind of reward is that? I've created this separate being that doesn't want to be connected to other beings? What are we going for here? I'm very much of the opinion that creating this trust right now will create an independent adult and that independent adolescent when it's time to be independent. Right now they need to know that I'm always here.

Emily didn't qualify her statements with allowances for different families like some other participants. Later in her narrative, she talked about how all mammals sleep with their babies. Speaking of her dog who slept in the bed with them but never too close to the baby, she said, "It's like they know cause they're mammals and they did that too with their moms."

Emily said at work she had been encouraged to support the "ABCs" of safe sleep. She found this difficult because most of the families she worked with were not from the U.S. and shared a bed with their children regularly. She wanted to be honest with the families and tell them that she also slept with her baby, but this meant going against work policy. She talked about how there were missed opportunities to discuss safe bed-sharing because everyone was

acting like no one was bed-sharing. Emily felt that both pediatric providers she had visited each implied that they knew families were regularly bed-sharing, but that they couldn't recommend anything but separate sleep. She explained,

> We act like what happens in the U.S. is normal everywhere and it's so not. We are the abnormal ones…. It kills me to have to talk to [my clients] about ABC's of sleep. It's so hard to be like, [whispering] "I do this, okay." But I'm not gonna lie. If they ask me, "what do you guys do?" I say, this is what [my workplace] is telling me to tell you. But this is what I do. If they ask. So it's like, can we just get another narrative going so that I don't have to lie to these people?

Emily thought many providers felt the same way she felt. She thought they needed permission to teach people how to share a bed with their baby safely. She ended her narrative saying, "I think there needs to be an alternative narrative…there is a safe way to do this but we can't talk about that if we're still acting like nobody bed-shares."

"Darcie:" "It's not a question of 'if.' It's 'when?'"

Darcie's narrative had the feel of a memoir of small town life. She had always lived on the same street. The main characters in her story included other moms, her pediatrician, and her sibling's family.

Darcie was a stay-at-home mom who did not stress a "natural" approach to parenting; rather, she stressed practicalities. She wanted all the modern conveniences of childbirth for all of her births. She was aware of the risks associated with bed-sharing, but her child would not sleep, so for one month, Darcie slept with her baby in a recliner. She didn't know at the time that this was more dangerous than sleeping in a bed; rather, she thought it was an effective way to avoid bed-sharing.

When it came time to have her second child, she planned to bed-share from the beginning. Darcie did not use any barriers in the bed other than her own arm, which stayed between her baby and her partner. She bought a king-sized bed, never placed the babies near any pillows and used minimal blankets. Her partner never had much of an opinion on the arrangement, as Darcie says they didn't have a lot of experience with babies.

Darcie was always honest with her providers when they asked about sleep space. Her first provider recommended against bed-sharing, but her new provider was supportive of safe bed-sharing. Darcie was the only participant to report that she spoke with a traditional medical provider about ways to safely share a bed with her baby.

Darcie believed bed-sharing was more common in her community than anyone admitted. She said, "I think some people don't want to say that they did it because they are afraid of the backlash." After this statement, she told the story of another mother at her church who commented that she didn't think Darcie had regular parenting problems like the rest of them. She said she thought Darcie thought she was better than everyone else because she practiced baby-wearing and cloth diapering. Darcie responded,

> "What do you mean? Who doesn't have those problems? I just did that to save money." I think once she saw that I'm the same as her except for some of the choices I made, she was like, "oh, ok."

Unlike other participants, this story seemed to illustrate that Darcie didn't feel judged by others in her community; rather, she felt that other people saw her as more dedicated to her children because of her choices. She didn't mention bed-sharing in this story, but the story was sandwiched right between two statements about bed-sharing: one about parents who hid bed-

sharing because of fear of backlash and another about how she believed that most people shared a bed with their child. She said,

> almost everybody I've talked to has let their baby sleep with them at some point. I don't know anybody who's been able to bring their baby home and get them in their own bed and if they do, they need to write a book. It doesn't happen.

Darcie hadn't slept with her children with the goal of creating independent, securely attached adults, although she thought this could be a consequence of the practice. She slept with them for "necessity, to get some sleep." Although she was anxious at first, she thought,

> What if I do everything I know to do that's safe and I still roll over on them or something? But once I started doing it, I felt like there's no way I'm gonna do that. It didn't feel like that was even a possibility. 'Cause it's almost like I was asleep, but I could feel them breathing, I could feel them nursing.

She emphasized that she was not a "stereotypically all-natural" type person. "I breastfed because I just wanted to do it. It saved me money." Similarly, she said she wore her babies because it was easier when getting in and out of the car and that she had "cabin fever" and wanted to meet other moms in a local baby-wearing group.

Darcie thought her sister was sleeping with her own infant on a large couch. When her sister's child was born, Darcie told her, "you will end up sleeping with them. It's not a question of 'if, it's 'when.' You might try to drive yourself crazy and try to get them in their bed, but it's not gonna happen."

"Jacqueline:" "The bond became the driving force."

Jacqueline quit her job to homeschool her children on their farm. Like Jennifer, her story had the feel of a romance between herself and her children. She teared up speaking about the

closeness she shared with them. There were fewer characters in her story compared with the other participants and she placed a larger emphasis on the intrapersonal aspects of her experience.

Jacqueline planned to put her first child in a crib because of health care professional recommendations and a fear that they would never leave her bed. However, from the first week of night-time nursing, she wasn't getting any sleep. She said,

> they wouldn't sleep for longer than 20 minutes at a time, it's just so hard to not go into the temptation of letting them go into the bed with me. And I thought it was the bed that was the unsafe place. So I took them to the recliner with me and I would recline with them, thinking that might be safer.

When her second child was born, she brought them into the bed from the beginning but experienced a lot of anxiety while bed-sharing. She would often pat her baby in her sleep, panicked that they had died in the night. She was not sure why she experienced so much anxiety with this child but says she had an incident in the hospital that may have created anxiety. She fell asleep while nursing this child in the hospital and the nurses "got onto" her, which caused her to think that bed-sharing must be worse than she thought. She pointed out that this didn't ever make her stop bed-sharing; she was just more anxious.

With her last child, Jacqueline said there was no question that she was going to bed-share; this time, she had no anxiety about the situation. She said she thought the lack of anxiety was being a "seasoned mom, [laughing] You just deal with it. I know what I'm doing." Her babies always slept "in the crook" of her arm in the middle of the bed, between her and her partner. This was primarily because she was afraid of them falling off the bed. Her partner never

had any anxieties about the situation and initially encouraged her to bring the baby to bed so she could sleep. They both felt they always slept lighter with the babies in the bed.

Jacqueline was ashamed to admit that she always lied when the provider asked if the babies slept in the crib. She would tell her other children that she was going to lie to the provider when they asked. With this story, Jacqueline stayed focused on her own thoughts and feelings; she never mentioned anything about the provider. For her, this was about how she felt and what lying about bed-sharing meant to her and her family. She seemed to assume that the providers were just doing their job. She explained what she was thinking at the time: "I already know what they think and I already know that it's not gonna change my mind cause we've done it for so long." Amongst her friends, she said bed-sharing was not a big topic. She didn't want medical professionals to know how she was sleeping but with friends she said, "I mean you just do whatcha gotta do. It's within our homes so, you know." For Jacqueline and her friends, what was done within the home was private.

Jacqueline described her parents as supportive of bed-sharing even though a member of the family lost a baby to suffocation while bed-sharing. They thought it was from being overtired so because they felt there was a reason, Jacqueline and her parents weren't worried.

Throughout the narrative, Jacqueline interspersed reminiscences of the cuddling, bonding, and comfort she felt sleeping with her babies and this seemed to dominate the tone of her stories. She used the word "bond" eight times throughout the narrative. She said,

> At first it's convenience, but the bonding and the cuddling and the closeness…it became the driving force. I miss sleeping with my babies. That was one thing I looked forward to when I was pregnant with them is nursing and being able to sleep with them… I think it's made them softer and more considerate and maybe

> that equipped them to make those stronger bonds even with other people, not just with me and my [partner]. I think it helped mold them into who they are.

"Marcy:" "I had a comin' to Jesus meeting with myself and I said, 'This is not gonna work.'"

Marcy's narrative was a drama with a clear peak involving the resolution of conflict and a happy ending. The main characters in her narrative included her provider and her co-workers.

Marcy used to work as a bedside nurse. She was aware of safe sleep guidelines and had cared for families who lost a baby to sleep-related suffocation. Initially she put her child to sleep in a crib because of her fears. She tried to do this for about one month after the birth. She struggled with breastfeeding because she was not making enough breast milk and her mental health started to suffer. Marcy felt like she was going down the path to postpartum depression. Her partner encouraged her to bed-share from the beginning, but her experience as a nurse made her too afraid. She said, "I've seen dead babies come in, 5:00 in the morning, I didn't want that to be my story."

As her sanity waned, some of her more experienced nursing friends came to her and told her she had to do something to get sleep. She said,

> We actually took a nap. That was the first step after they came and had my come-to-Jesus meeting with me. We had a nap and I was like, I could do this. This is not unsafe. We both slept good.

She said from this point on, her mental health improved and they slept each night. She also said that two days into co-sleeping she began leaking milk between feedings because her supply was so overwhelming.

Her provider was not supportive of her decision to bed-share. She said,

> They pretty much told me that it was against the law. They went down that road and I was like, "Show it to me in print"…Cause at some point you have to realize that I'm the mom and this is my child and I'm gonna do what's best for us.

She switched providers after this incident. She also changed her recommendations to patients. She said, "when I went back to the bedside, I would tell patients, 'This is the recommendation,' but I would also say, 'You have to do what's best for you.' Cause that was helpful for me to be like, AH!"

Marcy felt like the sleep-related infant death cases she had seen were correlated with cognitive impairments, exposure to smoke, and babies sleeping with individuals who were not their parent. She remembered commercials that talked about SIDS, but that the reality was that some parents were too tired to consider anything other than how to get sleep. She felt like in her area "there are a lot of people who smoke. If the mother is not smoking, they don't have a consistent relationship pattern so it may not always be the father or the primary caregiver that's co-sleeping with them." Marcy thought this was why deaths were higher in some areas of Appalachia.

While Marcy's nursing background influenced her initial fears about bed-sharing, she mentally decompensated after her son's birth and felt like she had no other choice but to bring him to bed if she wanted to breastfeed and sleep. The phrase "comin-to-Jesus-meeting" literally refers to tent revivals when preachers would travel around hoping to lead people to Jesus. The phrase represents a major turning point when someone realizes a truth and makes a change. A few other participants used this phrase in their narratives, in relation to issues other than bed-sharing, which highlighted the ubiquitous nature of religious influence in the region and the epiphanies that occurred when they became a parent. Marcy summed this up by saying,

> We attempted to sleep in the crib, but it never worked…I bought a bassinet cause I wanted him just to be in the room with me. That didn't work. So that's why I put him in the crib. I had planned for him to sleep in a bassinet and breastfeed, but it didn't work…so I had a comin'-to-Jesus meeting with myself and I said, "This is not gonna work."

"Rebecca:" "The first few months after birth is the fourth trimester…your baby has a biological need to be close to you."

Rebecca immediately started her narrative by talking about bed-sharing. The plot of her narrative was cerebral, filled with evidence of deep thinking and integration of research in her parenting decisions. It seemed she had spent a lot of time organizing her thoughts and the justification for her decisions. She was one of the few participants who talked about the future in her narrative.

In this study, it was rare for participants to think about bed-sharing before the baby was born, so it stood out when Rebecca said she and her spouse researched and solidified this decision while pregnant. They decided they wanted to follow an attachment parenting approach which involved co-sleeping. They had a cradle that was a family heirloom so they put their child to sleep there initially. The baby slept there successfully for a few months. Rebecca told the story of the night her child came into their bed:

> They nursed and then I went to put them back in the cradle and laid down and it was like their eyes, they were like one of those baby dolls except it was in reverse. The eyes just opened and so I'd sit there and rock them and rock them. And then I was like, okay, maybe if we put them back in the bed for a few minutes and let them snuggle, they'll fall asleep and you know, put them in the bed, their eyes

> immediately, immediately closed. Laid there for a few minutes, picked them up, put them back in the bassinet—"bing!" —and they just opened up. [Laugh] That's kind of how it started cause we were like, okay, we're just gonna let you sleep in the bed this night. And then it just kinda took off from there and then they wouldn't go to sleep in the cradle after that.

Her other child slept in the bed from the time they got home from the hospital. At the hospital, Rebecca said they weren't allowed to bed-share. However, when she came home, she said she only felt comfortable with them next to her in bed. She said,

> The anxiety was such that I needed to be close to them all the time to feel—it was like needing to make sure they were safe and I knew if they were close to me they would be safe, you know?

Rebecca was sure to include her feelings that bed-sharing was important when her children were sick, although this did not come up in the natural course of her stories. Before the close of her interview, she made sure to emphasize that she could not imagine sleeping separately from her children while they were sick because she did not feel she would be able to respond to them appropriately. She never felt any anxiety about bed-sharing because she had read studies and found that "the risks lie with just being irresponsible basically…I'm gonna do everything to make this the safest co-sleeping experience possible."

She described how she had a hard time sleeping when her partner would come home late due to work "cause it's like your whole family unit isn't together. You really want to make sure everybody's safe and gets home okay…even an adult doesn't want to sleep by themselves." She thought this closeness during the night would transfer to the future, influencing her kids to feel comfortable coming to them with anything.

Rebecca never had any conflict with her partner about bed-sharing. Rebecca felt like they agreed on everything, but she did not think this was the case for a lot of her married friends. She said, “the mom will decide what gets to be done. And I think it’s more just because the dad doesn’t feel like putting the energy into it in whatever way. Like whether it’s implementing it or arguing it.” In contrast, Rebecca said she and her partner played an equal role in the decision to bed-share with each child.

Rebecca didn’t think bed-sharing was much different in her area than it would be across the U.S., although she thought that people were not fully informed on a lot of issues and fell prey to “fear-mongering.” She wished there were clearer studies on how to bed-share safely so there could be stronger evidence to give people who didn’t understand. Despite everything, what stood out most in Rebecca’s narrative was the focus on the careful consideration of research. She explained, “we read about the first few months after birth is the fourth trimester and you don’t just want to separate—your baby has a biological need to be close to you.”

Avery: “I never wanted my child to sleep in the bed with me.”

Avery’s narrative went straight to the point. The plot came across as a mixture of memoir and drama with some shades of sadness. The main characters in her story included her ex-spouse, midwife, parents, and provider. She was one of the few participants to discuss her own bed-sharing situation as a child.

Avery slept with both parents until she was 12 years old. She said that is when she “discovered that there were no more monsters under the bed” and never went back to their bed. Avery felt her bed-sharing affected her parent’s marriage, which foreshadowed her later feelings that bed-sharing with her child affected her own marriage. Because she noticed the effect bed-sharing had on her parents’ marriage and she knew of the dangers of bed-sharing from her

background as a nurse, she "could have never imagined sleeping in the bed" with her child. However, she quickly found herself bed-sharing because of exhaustion and a drive to be close to her baby.

Avery said she was anxious the entire time she shared a bed with her baby. She placed her child on a firm pillow at one end of the bed while she and her partner slept down toward the other end of the bed to avoid the risk of overlying. Even though Avery stopped breastfeeding after a few months, she still felt it was easier to bed-share. Her child transitioned to a crib before 12 months of age but started bed-sharing again when Avery and her partner divorced. She said, "as a parent who never could have considered co-sleeping with my baby, I also went through a phase prior to remarrying where I could never imagine sleeping without my baby in the bed."

Avery said her obstetric provider initially appeared to be against bed-sharing, but once this provider said to a group of parents: "I understand it is the culture that we should not be co-sleeping, that it is not safe…but from personal experience, good luck with that. They all end up in the bed with you." Her pediatric provider asked at every visit if the baby was sleeping alone and Avery always told the truth. Each time, they would give her a little safe sleep board book, the same book Avery gave to parents in her job as a nurse.

Avery repeated that she was strongly against bed-sharing but ended up bed-sharing regularly. Avery remembered having multiple nightmares that her baby wasn't breathing during the night. The emphasis on infant death during sleep didn't work to deter her from bed-sharing, but it did cause her tremendous anxiety and nightmares about smothering her baby. She said, "I felt like I was waking up every hour putting my hand on them to see if they were breathing." In the end, she felt that bed-sharing had a negative effect on her marriage and though she "never wanted [her] child to sleep in the bed with [her]," she missed the closeness they had shared while

bed-sharing and felt it created a closer bond between her child and both herself and her ex-spouse.

Discussion

Participants used multiple plot types to describe their bed-sharing experiences. There were two memoirs and two romances. All of the other plot types were represented only once, although some could be called varieties of drama: cerebral, coming-of-age, comedy, informational, drama, persuasive, autobiography, and Joycean stream-of-consciousness. Individuals made meaning of their bed-sharing experiences in various ways. Few participants discussed the future in their narratives. This may represent their attempt to tailor responses to what they thought the interviewer was interested in studying, but it is also possible that bed-sharing was more about present-focused problems rather than future outcomes for these participants. Most narratives focused on interpersonal interaction, but for participants who told romantic stories, there was more about intrapersonal feelings.

Almost all participants told their birth stories at some point in their narrative. Sometimes their births represented wishes to approach life from a natural stance with little medical intervention. In other cases, the stories came forward because they were so closely tied to the bed-sharing topic. About half of the participants talked about refusing vaccinations. This may be because parents who take a strong natural parenting approach are more compelled to participate in a study about bed-sharing. It was clear that many of these individuals had strong viewpoints and wanted to share their stories. It is probable that others with milder views were not compelled to contribute to this study; in fact, one of the participants who did not identify as “natural” initially hesitated to participate because she felt she didn’t have much of a story to tell.

Few participants thought about their child's sleeping arrangements before the birth. They often assumed they would put the child in a bassinet or crib but found this difficult to implement in reality. Many had not prepared their bed in advance for an infant even though there are many guidelines that can greatly reduce risks associated with bed-sharing. One of the most important findings revealed in these narratives was the worry parents had about their infants falling off their bed. In every case where this was mentioned, the caregiver did something that actually made the sleeping environment more dangerous. Caregivers talked about installing bed rails on adult beds as an important safety measure to prevent falls, but bed rails on adult mattresses create wedging and suffocation risks for young infants. The average adult mattress is too soft compared with approved baby sleep surfaces and a bed rail on one side makes for a perfect suffocation hazard. The same situation occurs when an adult bed is pushed against the wall on one side.

No participant mentioned removing their mattress from the bed frame. Bed frames create wedging hazards and risks from falls. If bed frames are removed and the mattress is placed directly on the floor, these problems can be avoided. There is a way to measure the softness of an adult mattress to purchase one that is safer for an infant (Somers, 2015). None of these participants mentioned this test. Other hazards included pillows or towels placed on the edge of the bed or between the baby and the participant's partner. None of the participants mentioned the risks involved with these measures, although they did mention removing other pillows and blankets from the baby's environment.

Some participants felt that people in their surrounding communities were misinformed and judgmental toward more natural parenting styles, which included bed-sharing. However, other participants felt that bed-sharing was seen was a private matter that should be decided within the home. The participants who felt judged had all lived outside of the Appalachian region

at some point. All of the others who didn't feel that bed-sharing was an important issue among friends had lived in their community all their lives. Perhaps the other participants were able to compare other places that were more open to various lifestyle choices. Another possibility is that the participants who had moved out of the region had lost connections with close friends when they moved, exposing them to feelings of lack of support and belonging.

Despite the different feelings about peer support around bed-sharing, all participants were aware of the lack of support for bed-sharing among health care providers. Overall, participants dealt with this situation by lying, not always to avoid being reprimanded but sometimes just to avoid the inconvenience of extra discussion. A few participants were honest with their providers, but this usually occurred when they knew the provider was sympathetic to their situation or were confident about their knowledge of the topic. While all but one participant was advised against bed-sharing by providers (the other never saw a provider), none of them changed their behavior because of providers' recommendations. Rather, they were more likely to become frustrated or have increased anxiety after being counseled on safe sleep. The participants who had nightmares or awoke repeatedly in the night thinking their child had died had all known a person affected by infant sleep-related death or had been involved in a previous infant sleep-related death. However, they all reported that they never changed their practices because of these anxieties. Fear did not change their bed-sharing behavior.

The term "research" was used several times across different narratives. For some, this meant reading widely on the Internet. For others, this meant reviewing peer-reviewed studies. However, none of the participants revealed that they had training in advanced research methods. In contrast, physicians and other health care providers have advanced degrees and a lot of experience evaluating peer-reviewed literature. Despite this, many participants felt that they were

better equipped to evaluate research and determine the best course of action for their family. Some of these participants displayed a mistrust of medical authorities; many believed that interventions were pushed onto members of society through the health care system for ulterior motives like greed or control. The rising anti-vaccine movement supports the idea that there are many people who no longer trust authority or the meaning behind advanced degrees. Some people feel that everyone is on an equal playing field now that there is widespread access to information via the Internet. They do not seek out advice from professionals; rather, they take it upon themselves to peruse the Internet and make conclusions. These caregivers refused recommendations quickly and with confidence. There is usually not enough time in an office visit for providers to impart the kind of knowledge that years of training and experience can provide. There is also not enough time to develop complex relationships based on trust. There is not an easy answer to this problem, but it should continue to be investigated.

Limitations

This study used an interpretive framework and results would differ slightly if the data were analyzed by a different researcher. In narrative inquiry, this interpretive component is considered throughout the process and researchers do not attempt to bracket themselves out, yet remain an active, aware co-participant in the research (Riessman, 2008). Thus, the PI's role as a nurse may have had an influence on the participant's stories, although their openness seemed to suggest that this was not an important barrier. The focus of the study was limited to bed-sharing, which constrained what was told by participants. The results would have differed if the interviewer asked participants more generally about infant caregiving. Furthermore, participants were purposefully recruited through Facebook and may have been more homogenous due to Facebook network connections and internet access. While some of the participants had been to

the same midwife group during pregnancy, there were also several who were not from this group. It is probable that these families were more passionate about bed-sharing and, thus, shared different views than other caregivers who did not volunteer for the study. Finally, the authors had to exclude a lot of information from the final report as the data were profuse and often included details that would have revealed the identity of participants. The authors minimized the effect this had on the results whenever possible; this is a necessary limitation of any method with few participants and rich data (Saunders et al., 2014).

Validity

There are some limits to the validity of narrative inquiries, just as there are limits with any study. In narrative inquiry, the researcher asks whether the story reflects the experiential meaning for the participant accurately. Thus, the researcher admits that memory and story-telling place limitations on accuracy. However, this does not affect the accuracy of the explanation of meaning for the participant. There are limitations to stories that are told. Polkinghorne (2007) provides a useful outline of these limitations. First, language is constrained and cannot perfectly represent the experience that is reflected upon. The participant can only reflect meaning within the constraints of symbolic language. Second, the participant is not always consciously aware of every portion of their experience that has meaning. Third, participants often attempt to present a positive image of themselves to the interviewer and may not reveal every portion of their experiential meaning. Finally, the results of a narrative inquiry do not purely reflect the experience of the participant (Polkinghorne, 2007). The results emerge as a co-production between participant and researcher. Participants may read the body language, utterances, and what they know of the interviewer to frame responses. All of these issues were considered throughout this study and should be considered by readers.

Effects of the researcher on the participants

The interviewer was a pediatric nurse practitioner and doctoral candidate in nursing and participants were given this information during the informed consent process. Because all of the participants were aware of safe sleep guidelines, they may have altered what they told the interviewer due to her background. However, the interviewer was careful to remain non-judgmental, encouraged the participants to be open, and reminded them that she had been a parent, too, and understood their struggles. The interviewer assured the participants they would remain anonymous and that it was important for other health care providers to hear their stories. The interviewer has had many years of experience working with families from diverse backgrounds and was careful to convey neutrality on all topics discussed during the interviews.

Conclusion

Providers should be aware that families may lie or give idealized answers to medically relevant questions, especially when they do not feel supported. Caregivers may experience immense anxiety when bed-sharing, although they don't know how else to deal with overwhelming sleep deprivation and the admonishment to breastfeed but sleep separately. If providers do not talk with families about how to implement safe bed-sharing, caregivers may inadvertently create environments that are more dangerous for infants. Public health scare tactics may not work to decrease bed-sharing behavior and may only increase anxiety and cause families to be more apt to lie to providers. There are many caregivers who do not trust health care authorities and believe that anyone can become an expert because of access to the Internet.

Providers need more studies of caregiver experiences to understand how to connect with families in meaningful ways. Families need realistic suggestions about how to breastfeed and maintain close proximity to their infants safely. If bed-sharing deaths occur in situations where

there are no major risk factors, these instances should be publicized. Many caregivers in this study did not believe suffocation occurred unless a caregiver was impaired or smoked. It is not easy to determine from current research how often low-risk deaths actually occur, although public health messaging suggests otherwise. Providers must determine a better way to support families in their night-time infant caregiving and to re-open the lines of communication around infant sleep spaces.

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CONCLUSION

This dissertation consists of three articles about infant-caregiver bed-sharing. The major risk factors that increase the risk of infant death while bed-sharing were reviewed in the introduction. Part I contained a manuscript about multidisciplinary theory integration in bed-sharing research and highlighted epidemiological and evolutionary views on infant-caregiver bed-sharing. Part II consisted of a systematic qualitative meta-synthesis of caregiver-infant bed-sharing experiences. This meta-synthesis revealed three common themes in caregiver reports of bed-sharing experiences: responsiveness, practicality, and interpersonal negotiation. Part III presented the results of a narrative analysis of Appalachian caregivers' experiences bed-sharing with an infant in the last five years. The narratives of 12 participants from various Southern and South-Central Appalachian counties were presented. Most of these narratives were situated in the recent past and present and there were several plot types represented, highlighting that bed-sharing is experienced in many ways by different people. These articles have various implications for research, practice, and policy.

Implications for research

In Part I, the authors stated that nurses should lead a multidisciplinary integration of bed-sharing research to develop novel ideas. This could translate into studies that acknowledge both the risks and benefits of infant-caregiver bed-sharing. Nurses have integrated attachment theory (Bowlby, 1982) into their practice for years and are well positioned to advocate for caregiver-infant proximity while also being aware of contextual risks for infants. Furthermore, scholars should compare infants who sleep separately versus those who sleep in direct contact with committed caregivers in low-risk environments.

The results of the meta-synthesis presented in Part II showed that most parents experienced bed-sharing as an expression of caregiver responsiveness. In contrast, another review of bed-sharing research suggested that the most common reason for bed-sharing was breastfeeding (Ward, 2015). Although this was also a theme to emerge from the qualitative meta-synthesis in this manuscript, participants emphasized responsiveness to infant emotional, safety, and caregiver instinctual needs as the strongest factors associated with their bed-sharing experience. McKenna (2012) has hypothesized that bed-sharing may confer protection against SIDS. It is clear from the meta-synthesis that some caregivers expressed an instinctual drive to keep infants close to confer protection (see Part II). Thus, this hypothesis should continue to be explored with more studies of low risk caregiver-infant contact during sleep. Studies should clearly report all major risk factors involved with infant bed-sharing deaths. This will necessitate the development of more stringent methods for gathering drug and alcohol use data.

Part III presented the results of several types of caregiver bed-sharing stories and highlighted the myriad ways individuals experience bed-sharing. It is important to continue to explore regional and sub-cultural differences in infant sleep practices to tailor health recommendations to different groups. Researchers should continue to seek stories of caregiver experience to provide further insights into the meaning of health behaviors in unique circumstances.

Participant stories revealed many risks for infants that may be under-recognized. Infants may be exposed to unnecessary risks through the use of bed rails on adult mattresses and the use of bed frames and extra pillows. These devices were referenced by participants as methods to keep infants from falling off elevated beds or to separate infants from a bed-sharing partner.

Researchers should gather data on the use of bed rails, adult mattress softness, and the interaction between non-breastfeeding bed-sharing partners and their infants while asleep.

Implications for practice

Providers should be aware that there are families who are going to share a bed with their infant despite recommendations. It is more effective to be open with families and give them advice on safe bed-sharing rather than to ignore the issue and only recommend bed-sharing abstinence. Providers should tell families that there are certain risk factors that should be eliminated or reduced.

Families may lie to providers about their infant's sleep arrangements. A study by Levy et al. (2018) found that 81.1% of their sample reported lying to a health care provider at least once. The most common reason for lying reported in this study was fear of judgment or to avoid a lecture by the provider (Levy et al., 2018).The second most common reason was to avoid hearing about the possible harmful effects of their behavior.

Palmieri and Stern (2009) have made several suggestions for increasing provider-patient honesty. One suggestion was for the provider to normalize the behavior and admit that some information is difficult to disclose. For example, the provider could say, "I have spoken with many families who have slept with their baby, either purposefully or accidentally. I cannot recommend bed-sharing but I understand that it can happen. Do you ever sleep with your baby?" This can be contrasted with the following: "Baby sleeps in the crib, right?" "You never sleep with your baby, correct?" and even simply, "Does your baby sleep in a crib?" Providers can also examine their relationship to the patient and realize that trusting relationships take time to

develop and they may be more likely to receive honest answers if they have open, friendly, established relationships with patients.

Providers should tell families that suffocation may be more of a concern than falls. Families may be using bed rails or large pillows on adult mattresses to prevent infant falls when they would be better off removing their mattress from the bed frame. Bed mattresses should be firm with tight fitting sheets, little to no blankets, and babies should have nothing around them. The mattress should be free standing and should not be against a wall, which is another potential wedging risk. Lambert et al. (2019) found that of the 12% of infant deaths attributed to wedging from 2011–2014, the most common location of death was between a mattress and a wall. Other locations of death included in-bed sleepers, gaps between mattresses and bed rails, and between bed frames and mattresses. Most of the suffocation deaths occurred due to a soft adult mattress (Lambert et al., 2019).

The reality is that breastfeeding is frequent, babies are unique, and caregivers have different struggles after birth. Providers need to listen to individual stories to know how to give effective advice. Families may bed-share for many reasons and experience bed-sharing in many ways. Some bed-share as part of a lifestyle committed to internal drives and natural parenting. These caregivers might feel strongly that babies should only sleep in contact with an adult caregiver. Bed-sharing is an integral piece of their life philosophies and is not easily dismissed with a short statement by a health care provider. Others may end up bed-sharing due to spiraling mental health and lack of sleep. In these cases, providers need to be ready to offer workable solutions when caregivers are exhausted and committed to breastfeeding. It is important to note that many caregivers already experience immense anxiety about bed-sharing, but do not know

what other choice they have to get sleep, breastfeed, and “make it through the night intact” (Culver, 2008).

Some participants in the study in Part III communicated general mistrust in traditional health care providers. This led them to seek health information independently. Jaiswal and Halkitis (2019) have suggested that medical mistrust is increasing and based upon faulty scientific information along with social inequality. Recommendations for decreasing medical mistrust include addressing health care disparities, involving diverse and underrepresented individuals in research in a collaborative way, and promoting efforts to allow for longer and repeated patient-clinician visits (Jaiswal & Halkitis, 2019).

In the study in Part III, several participants discussed feeling a lack of support. A few participants were careful to point out that they thought mothers were particularly harsh with one another and that support among families was severely lacking. One participant discussed loss of the “village” to help raise a child and another focused on overwhelming loneliness. Still another had plans for inserting herself into the lives of mothers with the hope that they wouldn’t feel as alone as she felt after the birth of her children. Although these stories came from few participants, they inspire more questions about the ubiquity of loneliness and overwhelm among young families. This loneliness was almost unbearable when combined with financial strain. This focus on inadequate support revealed an important implication: the need for a focus on proximate, rather than distal causes of infant death. This focus calls for policies that bolster family support.

Implications for policy

Policies on safe sleep range from community policies to wide-reaching national government policies. Two professional organizations have published statements on infant safe sleep in the U.S. The most important statement on infant bed-sharing in the U.S. is the safe sleep guideline from the AAP (AAP Task Force on SIDS, 2016). The other publication is a position statement from the American College of Nurse Midwives (ACNM, 2017), which conflicts with some parts of the AAP's guidelines (ACNM, 2017).

The latest revision to the AAP's safe sleep guidelines was published in 2016 and included some major changes from the initial statement (AAP Task Force on SIDS, 2016). The AAP does not support any bed-sharing but admits that bed-sharing often happens inadvertently in the first few months of life, especially in relation to breastfeeding (AAP Task Force on SIDS, 2016). The previous AAP guideline may have led to an increase in the proportion of infant deaths attributed to suffocation in sofas and chairs because parents were trying to avoid falling asleep in bed with their babies. In the new statement, the AAP recognized this issue and recommended caregivers feed infants in the bed rather than on a chair or sofa when there is any risk that the caregiver will fall asleep (AAP Task Force on SIDS, 2016).

Another important change in the AAP guidelines involved the recommendation that infants sleep in the same room as the parents for the first year of life (AAP Task Force on SIDS, 2016). What is most notable in the report is the continued sparsity of discussion about preparing a low-risk adult sleep environment for those times when the infant will inevitably fall asleep with the caregiver (AAP Task Force on SIDS, 2016). The AAP may not want to appear to condone

bed-sharing; however, the ACNM position statement points out that this puts many babies at risk because parents are not educated on safe bed-sharing (ACNM, 2017).

The ACNM's (2017) position statement on safe infant sleep focuses on the difficulties faced by blanket anti-bed-sharing policies, especially related to breastfeeding mothers. The ACNM affirms that bed-sharing can be practiced safely but may be hazardous if practiced incorrectly. They even state that bed-sharing may be protective of SIDS if practiced safely by breastfeeding mothers (ACNM, 2017). Thus, they affirm that health care professionals should educate all women on "best practices for bed-sharing" (ACNM, 2017).

One source of safe bed-sharing information comes from McKenna (2018). McKenna postulated that low risk mother-infant sleep would lead to decreased risks for infant death unless it was altered by substance use or a sleep environment that was very different than the one our human ancestors probably used (a firm surface next to an unaltered breastfeeding mother that had been in contact with the infant for most of every day) (McKenna, 2012). McKenna and his like-minded colleagues have frequently commented on U.S. anti-bed-sharing policies and the unintended negative consequences these have for families (Ball, 2017; McKenna & Gettler, 2015). McKenna (2018) includes a section on his website addressing how to bed-share safely. The guidelines include removing the adult mattress frame, removing heavy bedding (mothers can wear onesie-type pajamas and eliminate sheets), ensuring the adult mattress is very firm (Somers, 2015), and ensuring a tight-fitting bottom sheet.

In addition, the infant should sleep next to the mother only (no siblings or animals) and ideally the mother will be an exclusively breastfeeding mother who did not smoke during pregnancy. There should be no second-hand smoke exposure in the home and no alcohol or drug

use by bed-sharing caregivers. Necessarily, recommendations about safe bed-sharing must include the information that if the primary caregiver is not breastfeeding, smokes, or uses any other substances that impair arousal, the infant must be placed on a separate but close sleep surface for every sleep (McKenna, 2018). None of this information on safe bed-sharing is referenced in the AAP safe sleep guidelines (AAP Task Force on SIDS, 2016).

The following professional organizations are associated with the health of peripartum women and infants, but have not published guidelines or policies regarding bed-sharing: the Association of Women's Health, Obstetric, and Neonatal Nurses (AWHONN), the American College of Obstetricians and Gynecologists (ACOG), the International Lactation Consultants Association (ILCA), the National Association of Neonatal Nurses (NANN), and the National Association of Pediatric Nurse Practitioners (NAPNAP). Most of these organizations endorse the AAP's safe sleep policy; however, ILCA has published a statement critiquing the anti-bed-sharing stance of the policy (ILCA, 2005).

Current national and state policies

Many national and state policies on bed-sharing are aimed at behavior change of caregivers using education or fear tactics. The most famous of these was the campaign in Milwaukee County, Wisconsin, which involved several photographs comparing infant bed-sharing to crime and murder scenes (Dennis, 2011). In Tennessee, infant safe sleep campaigns consist of public postings of babies in safe sleep spaces with the "ABCs" of safe sleep displayed (Alone, Back, Crib) on buses, in restrooms, and as decals on the floors of government buildings (Tennessee Department of Health [TDOH], n. d.). The Eunice Kennedy Shriver foundation National Institutes of Health and Human Development (NICHD) coordinates the national "safe

to sleep" campaign in collaboration with several other governmental and non-governmental organizations (NICHD, n. d.). The "safe to sleep" campaign sponsors education and outreach to spread safe sleep messages to families, including messages to always place infants on a separate sleep surface.

These campaigns assume the issue in infant bed-sharing death is lack of information. The campaign has been effective in ensuring families are aware of the stigma associated with bed-sharing in the U.S. but not as effective in decreasing sleep-related death (Ateah & Hamelin, 2008; Bombard et al., 2018; Stiffler et al., 2018). Many caregivers bed-share accidentally by falling asleep during one of the dozen or more breastfeeding sessions that occur every day in the first few months of life (Ball, 2007). Ball (2007) found that while most parents did not intend to bed-share when interviewed before birth, the majority were bed-sharing after the infant's birth. In addition, many caregivers reported that they did not believe bed-sharing was inherently dangerous (McKenna & Volpe, 2007). They felt an instinctual drive to stay near their infant (Stiffler et al., 2018). In a study of Black mothers in the U.S., most said they did not believe they were a risk to their infant and felt they were more likely to terminate a life-threatening event if sleeping next to their baby than if the baby were on another surface (Stiffler et al., 2018). McKenna and Volpe (2007) confirmed these ideas; many mothers described instances where they felt they terminated a life-threatening event in their infant while bed-sharing. The study in Part III of this manuscript presented stories of several caregivers who slept with their babies and did not believe their babies were at risk. They felt that their infants were safer next to them and that infants who died while bed-sharing were exposed to other major risks.

Despite professional position statements and state and national policies against bed-sharing, it occurs frequently; in 2015, over 60% of respondents to the U.S. Pregnancy Risk Assessment Monitoring System (PRAMS) admitted to bed-sharing (Bombard et al., 2018). New perspectives on infant sleep-related death data show that this is now an issue about social inequality. Most sleep-related infant deaths occur in minority populations situated in wealthy regions of the world with high income inequality (Bartick & Tomori, 2019).

Bartick and Tomori (2019) have discussed this issue from a syndemics perspective, noting that most of these deaths now occur in families with low socioeconomic status. The highest rates of sleep-related death in the U.S. are in Black and Indigenous infants (Bartick & Tomori, 2019). There are markedly low rates of infant sleep-related death in Sweden and Japan, where there is low income inequality, robust social programs, and high bed-sharing rates (McKenna & McDade, 2005).

Syndemics refers to a concept known as "systemic epidemics" and was coined by Merrill Singer in the 1990s (Singer et al., 2017). The idea is that there are clusters of disease entities that interact and exacerbate each other within populations at risk and that these issues cannot be addressed in silo but must be viewed from a larger lens. The most commonly studied syndemic is that of substance abuse, violence, and AIDS (Singer et al., 2017). To address the HIV crisis, all of the related inequalities must also be addressed. A syndemic view shows how social policies are needed to address proximate health issues.

The root causes of infant bed-sharing death may stem from the social determinants of health or inequality in the treatment of those who are poor and living with the chronic, toxic stress effects that come along with those conditions (Bartick & Tomori, 2019). These individuals

are more likely to smoke, use alcohol or drugs, and live in crowded conditions where the ability to stay warm and safe may be of more immediate importance than safe sleep advice (Bartick & Tomori, 2019; Haushofer & Fehr, 2014). Thus, the argument becomes much more complex than widespread anti-bed-sharing campaigns. Change will come with social change and this is how nurse leaders should engage with the issue not only to have an impact health outcomes in infant sleep-related death, but also for countless other health issues as well.

National and state policy development and implementation

There are several important ways that nurse leaders can advocate for policies to decrease infant sleep-related death. These policies include advocating for social programs to alleviate poverty, stress, and substance use in high risk families. A few of the social issues that would be important in reducing infant sleep-related deaths include paid parental leave (PPL), high quality early childcare, and social support for parents of young children living in poverty.

Paid parental leave

The U.S. is one of only two nations and the only developed nation in the world that does not mandate some form of PPL to families with new infants (Adema et al,, 2016). There are several options for a PPL policy in the U.S., including leaving the decision to offer this benefit to private businesses and encouraging states to adopt their own PPL policies. So far, these methods have failed to provide the majority of U.S. families with PPL (Adema et al., 2016), although this is changing.

The International Labor Organization recommends at least 18 weeks of paid maternity leave with a minimum two-thirds of pay; several countries offer more (Tanaka, 2005). All developed countries offer this benefit to birth mothers and many more extend the benefit to

fathers and adoptive or foster parents (Kaiser Family Foundation, 2020). Eight states and Washington, D.C., have PPL policies (Kaiser Family Foundation, 2020). In 2019, the Federal Employee Paid Leave Act was passed. This act gave 12 weeks of paid leave to qualifying federal employees. The provision of mandated leave to all American workers would amount to an average of a 0.5%–2% tax for each American worker (Gitis, 2016).

Families with the highest incomes are most likely to have access to and afford unpaid leave, with the most disadvantaged families receiving no leave benefits (Kerr, 2016). Paid leave policies benefit disadvantaged families most, while unpaid leave policies only benefit higher income families (Kerr, 2016). After passage of the Family Medical Leave Act (FMLA) in the U.S. in 1993, one study found a 10% reduction in infant mortality among those most likely to be able to afford the unpaid leave, with an almost 50% reduced incidence of ill-defined cause infant mortality, but no change among low-income single mothers (Rossin-Slater et al., 2012). In a study of child outcomes after four months of paid leave replaced three months of unpaid leave in Norway, children of mothers with low education experienced a doubling in benefits (Carneiro et al., 2015). PPL in the U.S. would allow for increased breastfeeding rates, enhanced attachment security in infants, reduced fatigue and stress in caregivers, and possibly reduced rates of smoking and substance use (Burtle & Bezruchka, 2016). Thus, implementing PPL would be likely to lead to a decreased rate of infant sleep-related death.

Early Childcare

In the U.S., Head Start programs provide early childhood education for pre-school children qualifying for free childcare based on the family's poverty level. Early childhood programs have been shown to reduce crime rates, save money, alleviate parental stress, and

enhance caregiver economic security (Heckman, 2011; Vallotton et al., 2012). Smoking and substance use rates are highest in populations with low socioeconomic status and are associated with increased chronic stress (Haushofer & Fehr, 2014; Young-Hoon, 2012). Policies that effectively provide for caregiver relief and enhanced opportunities for work and economic security should lead to decreased smoking rates and substance use. In addition, when families are not struggling to provide for basic needs, they are able to focus on more far-reaching preventive measures, like preparing a safe sleep environment (Haushofer & Fehr, 2014).

Support for Parents

While PPL and early childcare are both forms of support for young families, direct support from trusted professionals would also bolster resources and the ability to reduce risks in the home. Nurse visiting programs have been effective in improving infant socio-developmental outcomes and should be used in efforts to decrease infant sleep-related death (Health Resources and Services Administration [HRSA], 2016). These programs have led to improvements in state rates of overall maternal/newborn health, prevention of child abuse, family economic self-sufficiency, increased breastfeeding rates, and decreased rates of alcohol and drug abuse, among other measures (HRSA, 2016).

Nurse visitors could also more directly examine the sleep environment and make recommendations to families, including working to reduce as many risks as possible. The family should fully understand the risk-benefit profile of infant sleep safety and the specific ways in which they can continue to choose their infant's sleep arrangements while reducing risks as much as possible. This can be best achieved through an intimate relationship with a health care professional directly present in the home. Office visits may be too brief and impersonal to impart

all the relevant risk reduction situations available to parents. In fact, some of the participants in the study in Part III reported seeking out midwives for their births because they spent up to an hour in their home for prenatal visits, which allowed them to build trusting relationships.

Conclusion

Many of the risks involved with infant sleep could be eliminated by supporting families in disadvantaged situations. Nurse leaders can look to other regions of the world to see which policies result in the best outcomes for families and advocate for these policies to be implemented immediately in the U.S. Paid parental leave, continued quality early childcare programs, and social support for parents are all policies that will lead to reduced risks for families. This is the only way to see a reduction in mortality rates across the board and to lift those living in the most disadvantaged situations into a place where they can afford, both financially and psychosocially, to reduce risks.

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APPENDICES

Appendix A

Table A.1 Risks of infant-caregiver bed-sharing study matrix.

Study	Data Collected (Years)	Purpose	N	*Main* Findings	Major Limitations
Mitchell et al., 2017	2012 – 2015	Identify modifiable risk factors for SUDI in New Zealand	137 SUDIS / 258 controls – 73 (57.5%) bed-sharing / 46 (17.8%) controls	- **Overall** bed-sharing (aOR 4.96, 2.55-9.64) - **Smoking**: Bed-sharing + prenatal smoke exposure (aOR=32.8, 95% CI=11.2, 95.8) compared to bed-sharing + no prenatal smoke exposure (aOR 1.59, 95% CI 0.52 – 4.87)	The only interaction with bed-sharing explored prenatal smoke exposure.
Bugeja et al., 2016	2008 – 2010	Describe infant sleep-related death bed-sharing in Victoria, Australia	72	**Overall** bed-sharing 33 (45.8%) – **Alcohol/drugs**: 69.6% **No BF:** 42.4% **Unsafe sleep space:** 12.1% couch **Non supine:** 42.4%	Mostly missing info for smoke exposure and pillow exposure. -Does not describe combined risks
Blair et al., 2014	1993-1996; 2003-2006	Quantify risk of SIDS while bed-sharing without risk factors and understand risk interactions with bed-sharing	405 / 1387 controls	**Overall:** Bed-sharing without smoking, no alcohol or drug use, not on sofa/chair: aOR 1.1 (95% CI 0.6 – 2.0). < 3 mos: **overall** aOR 3.3 (95% CI 2.1–5.3) > 3 mos: **overall** aOR 0.1 (95% CI 0.01–0.5) **Alcohol**: aOR 6.38 (95% CI 2.38 – 17.12) **Smoking**: <3 mos aOR 8.93 (5.27 – 15.14); > 3 mos next to smoker aOR 1.42 (0.72 – 2.79) **Non supine:** aOR 0.4 (95% CI: 0.2–1.2) **Unsafe sleep space:** aOR 23.86 (52.2 – 109.2) sofa or chair **BF:** non-significant except for non bed-sharers which had aOR 0.3 (95% CI 0.2 – 0.5)	Excluded deaths labeled asphyxia or unknown? Drug use data not included in this analysis.

Table A.1 (Continued)

Study	Data Collected (Years)	Purpose	N	*Main* Findings	Major Limitations
Volpe et al., 2013	2002-2004	Describe how risky sleep behaviors occurred between 4 mothers and infants	4	**Unsafe sleep spaces:** Despite alternatives, these mothers slept: (1) on sofa (2) in bed with baby's head covered by blankets /pillow /hair (3) multiple blankets / baby pillow (4) continuous bottle propping and soft objects	No interviews – participants filmed in a sleep lab
Carpenter et al., 2013	1987-1990; 1992 –2003;	Quantify risk of SIDS for breastfeeding infants < 12 months without exposure to smoke	1472 / 4679 controls	**Overall:** Bed-sharing no smoking, no alcohol <= 3 months: aOR 5.1 (95% CI 2.3 – 11.4) / >3 mos: aOR 1.0 (0.3 to 3.0) **Smoking**: aOR 2.9 (2.3 – 3.6) both parents **Alcohol:** aOR 4.8 (2.6 – 8.9) mother **Drug use:** (maternal, illegal): no estimates for bed-share but 11. 4 (2.2 – 57.8) for room share **Nonsupine:** No change in risks by position in first 3 mos, at 20 weeks back position aOR 1.2 (0.6 – 2.8), side aOR 0.8 (0.3 – 2.0), prone 5.3(1.8 – 16.0) **No BF:** aOR 1.5 (1.2 – 1.8) **SS:** sofa sleeping infants excluded from analysis	60% imputed data for 3/5 data sets for drug and alcohol use
Baddock et al., 2012	Not given – first report from data published in 2004	Identify SaO2 <90% (desat) events and inspired CO_2 > 3% in bed-sharing versus cot-sleeping infants (0-6 mos)	40 bed-sharing/ 40 cot-sleeping	**SS:** Bed-sharing group had 6.8 desat events/night vs. cot group of 3.1 events for a risk ratio of 2.17 (1.75 – 2.69; p<0.001) with more desats with increasing infant temperature; No infant showed elevated heart rate with the events; 22 bed-sharing infants had rebreathing events versus 1 cot infant (wrap covering face) – no desats associated, most a/w head covering; **Nonsupine:** 5 bed-sharing infants spent some time prone (2 rebreathing face into pillow, 1 rebreathing face in mom's chest) versus 2 cot sleeping infants for whole night (no rebreathing)	Few smokers (8% bed-share, 25% cot), all but 5 cot infants breastfeeding; all term infants who are well, and not exposed to smoke or alcohol/drug use

Table A.1 (Continued)

Study	Data Collected (Years)	Purpose	N	*Main* Findings	Major Limitations
Collins et al., 2012	1999 – 2011	Determine causes and potential risk factors of infant mortality in Nunavut, Canada	117 total deaths / 33 bed-sharing deaths	**Overall** 33/47 were bed-sharing and 23 (70%) of those had 2+ risk factors (**non-supine**, sofa sleep (**SS**) **smoking** or **alcohol/drug use**). Other identified risk was bed-sharing with a non-caregiver.	Not all cases had bed-sharing information (9 / 56 missing this information); do not report on which and how many risk factors present per case
Vennemann et al., 2012	1984-2001; 2003-2006	Quantitative review of current evidence about SIDS – bed-sharing.	464 / 6495 controls	**Overall** aOR 2.89 (95% CI, 1.99-4.18) <12 weeks overall aOR 10.37 (95% CI, 4.44-24.21). Older infants 1.02 (95% CI, 0.49-2.12). **Smoking:** aOR 6.27 (3.94 – 9.99) (maternal); Non-smoking aOR, 1.66 (95% CI, 0.91-3.01)	Do not consider breastfeeding status, sleep on sofa/chair, non-maternal smoke exposure, or alcohol/drug use. Some were also done before the "back to sleep" era, also not controlling for position.
Ostfeld et al., 2010	1996 – 2000	Describe modifiable and non-modifiable risk factors present in SIDS deaths in New Jersey	244 (93 / 239 bed-sharing)	**Overall** 93/239 (38.9%) with relevant data were bed-sharing – only 5 (5.4%) had no other risks identified **Nonsupine:** 39.8% **Smoking:** 46.7% (maternal), 40.0% (father) **Sleep space:** 53.3% (presence of quilts, blankets, pillows, sofa, other children)	Did not describe combined risks– no measurement of alcohol or drug use

Table A.1 (Continued)

Study	Data Collected (Years)	Purpose	N	*Main* Findings	Major Limitations
Fu et al., 2010	1993 – 1996	Secondary data analysis of population-based case-control study of black infants dying of SIDS in Chicago	195 / 195 controls	**Overall** aOR 2.0 (1.2 – 3.4) **SS:** soft surface aOR 2.9 (1.4 – 6.3) **Smoking:** prenatal aOR 4.0 (1.9 – 8.5); mother non-smoking pregnancy aOR 1.7, (95% CI 0.8 -3.4); mother smoking current aOR 6.0 (2.7 – 13.4); mother non-smoking current aOR 1.9 (95% CI 0.9 – 3.8) **No BF:** aOR 1.9 (1.1 – 3.4) (current); breastfeeding aOR 1.1 (0.3 – 3.4) **Sleep space:** # covers 0 – 1 aOR 2.8 (1.5 – 5.2); # covers >=2 aOR 1.8 (0.8 – 4.1); soft seep surface aOR 8.8 (3.5 – 21.7); pillow use aOR 4.1 (1.4 – 11.5) **Nonsupine:** aOR 4.1 (1.7 – 9.7) – Adjusted for marital status, education, prenatal care	Some of the category numbers were small (breastfeeding infants = 40), no measurement of alcohol/drug use
Vennemann et al., 2009	1998-2001	Investigate sleep environment risk factors for SIDS in 11 out of 18 states in the Federal Republic of Germany- in that area, 50% of all births in Germany occur	333 / 998 controls	**Overall** aOR **2.81 (0.81–9.75)** **Nonsupine**: supine aOR 7.08 (3.69–13.60); side aOR 0.79 (0.47 – 1.34) **Unsafe sleep surface:** thick duvet aOR 2.20 (1.21–4.00), light duvet aOR 1.92 (1.07 – 3.45); pillow 1.03 (0.66–1.59); sheepskin 0.88 (0.47–1.68)	No data on alcohol use, maternal smoking in pregnancy and breastfeeding only included as controls and not directly tested, only asked about breastfeeding in first 2 weeks of life
Blabey & Gessner, 2009	1992 – 2004	Examine bed-sharing deaths and known risk factors (Alaska)	126 / 891	99% infant deaths occurring during bed-sharing involved at least one other risk factor and often more than one **Nonsupine:** 36% (30% unknown), **Smoking:** 75% (maternal tobacco) **Alcohol/drug:** 43% **Unsafe sleep space:** 14% sofa	8% of infant deaths reviewed were missing bed-sharing information

Table A.1 (Continued)

Study	Data Collected (Years)	Purpose	N	*Main* Findings	Major Limitations
Ball, 2009	Not given	Compare airway compromise in bed share vs cot sleeping infants	20	**Unsafe sleep space:** Airways covered bed-sharing (14/20) vs cot sharing (2/20) (Wilcoxon sign ranks test: p = 0.006) - No overlying -No significant differences in O2 saturation or HR when matched for (Wilcoxon signed rank tests)	Filmed in sleep lab. Purposive sampling of breastfed infants < 3 mos. Of non-smoking, either occasional or frequent bed-sharing parents

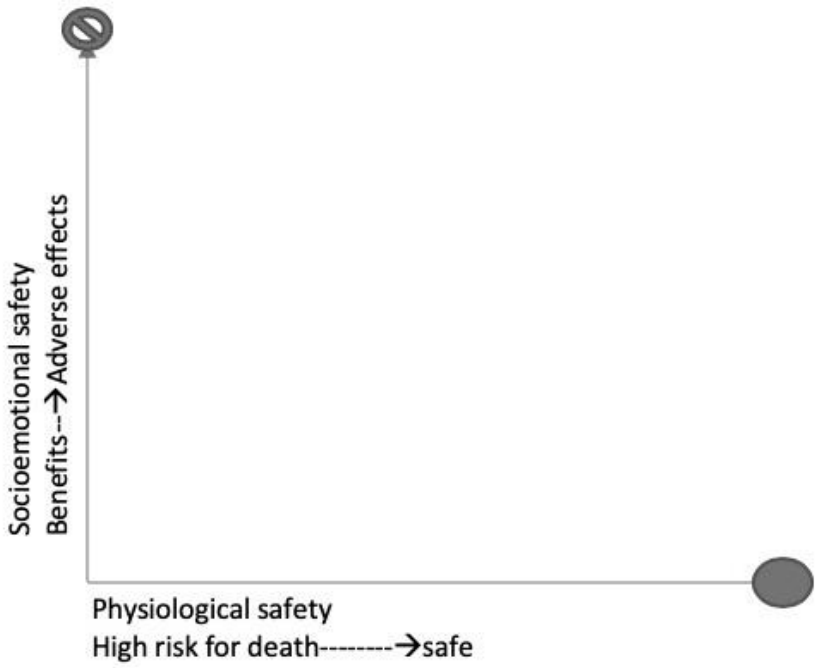


Figure A.1. Breastsleeping and the triple risk of bed-sharing. Socio-emotional safety is on the y-axis while physiological safety is on the x-axis. Moving from lower to higher on the y-axis, the adverse effects of sleep practices increase. Moving higher on the x-axis, infant sleep safety increases. Every infant lies somewhere in this plane of benefit versus risk. An infant located closer to the left on the x-axis and higher on the y-axis would have adverse socio-emotional effects of sleep as well as the highest risks for sleep-related death ( ). Infants on the right of the x-axis and lowest on the y-axis would have the most beneficial and safest sleep situation ( ).

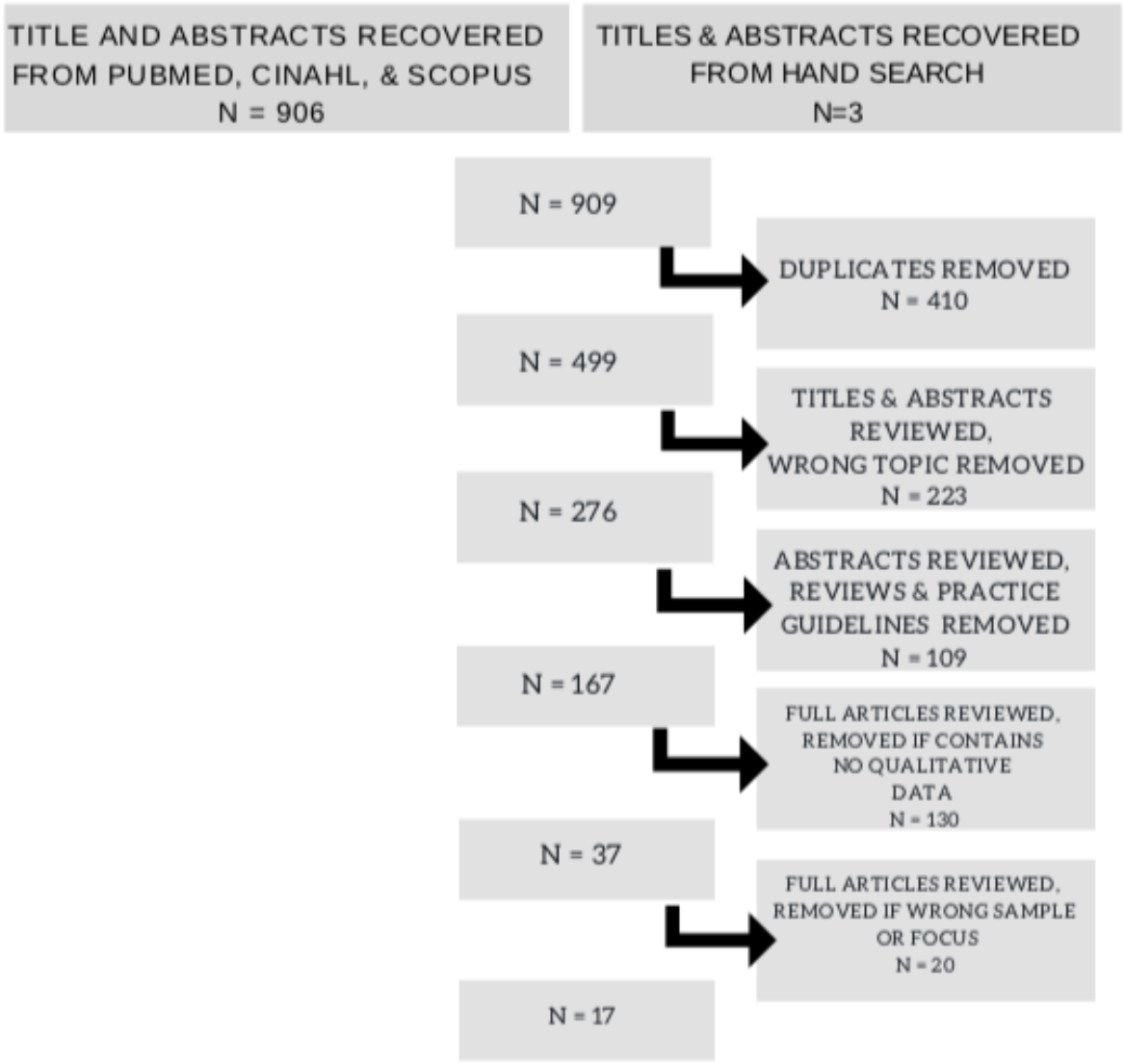


Figure A.2: Qualitative meta-synthesis search audit trail.

Table A.2. Qualitative meta-synthesis article summaries.

Authors\Year	Sample size	Setting	Data Collection	Methodology / Analysis	Study Purpose
Abbott, 1992	107 mothers	Eastern Kentucky county	Surveys, Interviews, participant observation	Ethnography / Not described	(Qualitative portion) To reveal mothers' feelings about and reasons for moving their children's sleep locations
Ball, Hooker, & Kelly, 1999	60 families 1st interview- 40 families 2nd interview	North Tees, UK	Semi structured face-to-face interviews before birth and at 3-5 mos of age	Mixed methods / Not described – field notes "coded" and put into computer spreadsheet	To compare data on the expectations and experiences of nighttime caregiving for parents having their first baby with those of experienced parents
Abel, Park, Ripene-Leach, Finau, & Lennan, 2001	150 caregivers / 37 focus groups / 2 one-on-one interviews, mostly women, mostly parents (8 grandparents), from 4 different ethnic groups	Aukland, New Zealand	Focus groups – 2 one-on-one interviews	Qualitative cross-cultural comparison / Thematic	To understand inter- and Intracultural differences in infant care practices among Maori, Tongan, Samoan, Cook Islands, Niuean and Pakeha (European) caregivers residing in Auckland, New Zealand

Table A.2 (Cont.)

Authors\Year	Sample size	Setting	Data Collection	Methodology / Analysis	Study Purpose
Ball, Hooker, & Kelly, 2000	Same data as 1999 article, but using 36 present fathers at 2nd interview when infant 3-5 mos.	North Tees, UK	Semi structured face-to-face interviews before birth and at 3-5 mos of age	Mixed methods / Not described – field notes "coded" and put into computer spreadsheet	To explore fathers' expectations and experiences sleeping with their babies
Hooker, Ball, & Kelly, 2001	Same data as 1999 article, 60 families 1st interview- 40 families 2nd interview	North Tees, UK	Semi structured face-to-face interviews before birth and at 3-5 mos of age	Mixed methods / Not described – field notes "coded" and put into computer spreadsheet	To reveal parental attitudes and experiences of infant nighttime sleeping strategies
Ball, 2002	253 families	NE England	Semi-structured interviews (infant 1 and 3 months), sleep logs	Mixed methods / Interview notes input into computer database and iteratively categorized	To reveal parents' reasons for sleeping with their infants
McKenna & Volpe, 2007	Over 200 breastfeeding mothers	Canada, US, Australia, and Great Britain	Internet-based survey with open-ended questions	Narrative ethnohistory /Not clear- thematic	To present parental reasons for bedsharing, evaluation of bedsharing and effects on family, re-define safe bedsharing, and to introduce the use of ethnographic data to inform public health problems

Table A.2 (Cont.)

Authors\Year	Sample size	Setting	Data Collection	Methodology / Analysis	Study Purpose
Chianese, Ploof, Trovato, & Chang, 2009	28 bed-sharing African American caregivers	US inner city	Audio-taped and transcribed focus groups	Grounded theory	To explore parents' perception of bed-sharing benefits, risks, and primary care provider advice
Joyner, Oden, Ajao, & Moon, 2010	73 African American mothers / 13 focus groups / 10 mothers interviewed	Washington, D. C. and Maryland	Audio and video taped one-on-one interviews and focus groups	Grounded theory	To investigate factors influencing decisions about infant sleep location among a socioeconomically diverse African American population
Gaydos, Blake, Gazmararian, Woodruff, Thompson, & Dalmida, 2015	7 focus groups (60 African-American mothers), 20 provider interviews	Atlanta and Albany, GA	Audio recorded focus groups and interviews	Qualitative / Content analysis	To compare sleep practice decision making for low-income, African-American women and what their providers tell them in order to prevent SIDS/SUID
Culver, 2008	24 bed-sharing mothers	NE & Central PA	Interviews-written and audio taped answers	Grounded theory / level I-III coding; concept development, modification, and integration	To develop a model that describes mothers' decision-making process to bed share

Table A.2 (Cont.)

Authors\Year	Sample size	Setting	Data Collection	Methodology / Analysis	Study Purpose
Shimizu, Park, & Greenfield, 2014	51 Japanese mothers	Japan	Public internet forum	Mixed methods / Coding a priori parental enthnotheory themes	To discover if parenting values and gender roles in Japan have moved away from roles ascribed by birth toward roles based on choice and individual differences
Tully, Holditch-Davis, & Brandon, 2015	56 women at interview 1 (26 late preterm and 30 term) and 45 of those women (22 late preterm and 23 term) at 1 month postpartum telephone interview	SE US medical center	In-person interview (at birth); telephone semi-structured interview at 1 month postpartum	Mixed methods / Iterative coding process	To describe parent-infant sleep plans (at time of birth) and reported practices of late preterm and term dyads at 1 month postpartum
Dodd & Jackiewicz, 2015	24 mothers	Perth, Western Austrailia	Semi-structured interviews; focus groups	Constant comparative constructivist grounded theory	To explore the experience of mothers in negotiating with their partners about bed-sharing

Table A.2 (Cont.)

Authors\Year	Sample size	Setting	Data Collection	Methodology / Analysis	Study Purpose
Caraballo, Shimasaki, Johnston, Tung, Albright, & Halbower, 2015	43 high school mothers in 7 focus groups	Colorado	Semi-structured focus groups	Iterative grounded theory approach to developing codes and themes	To explore the knowledge, attitudes, beliefs, and current safe infant sleep practices of adolescent mothers
Bailey, 2016	6 breastfeeding mothers	Urban Austrailia	Semi-structured interviews	Phenomenology / Broadly followed interpretive phenomenological analysis	To take an in-depth view of breastfeeding mothers' experiences of bedsharing with infants and young children
Jones, Barber, Nikora, & Middlemiss, 2017	10 Maori parents (8 mothers, 2 fathers)	New Zealand	Online survey, face-to-face interviews	Mixed methods / Thematic analysis	To describe what approaches Māori parents use to get their babies to sleep, and what factors they identify as influencing their decision-making process when selecting approaches

Table A.3. Critical Appraisal Skills Programme (CASP) evaluation for each article.

	Clear statement of aims?	Qualitative method appropriate?	Design match aims?	Recruitment match aims?	Data collection match aims?	Researcher - participant relationship?	Ethical issues considered?	Data analysis rigorous?	Clear statement of findings?
Abbott, 1992	?	✓	✓	?	~	x	x	?	✓
Ball et al., 1999	✓	✓	✓	✓	✓	~	✓	~	✓
Ball et al., 2000	✓	✓	✓	✓	✓	~	✓	~	✓
Abel et al., 2001	✓	✓	✓	✓	✓	✓	✓	~	✓
Hooker et al., 2001	✓	✓	✓	✓	✓	~	✓	~	✓
Ball, 2002	✓	✓	✓	✓	✓	~	✓	✓	✓
McKenna & Volpe, 2007	✓	✓	✓	✓	✓	~	✓	~	✓
Culver, 2008	✓	✓	✓	✓	✓	✓	✓	✓	✓
Chianese et al., 2009	✓	✓	✓	✓	✓	~	✓	✓	✓
Joyner et al., 2010	✓	✓	✓	✓	✓	~	✓	✓	✓
Shimizu et al., 2014	✓	✓	✓	~	✓	✓	x	✓	✓
Dodd & Jackiewicz, 2015	✓	✓	✓	✓	✓	~	✓	✓	✓
Tully et al., 2015	✓	✓	✓	✓	✓	~	✓	✓	✓
Bailey, 2016	✓	✓	✓	✓	✓	~	✓	✓	✓
Caraballo et al., 2016	✓	✓	✓	✓	✓	✓	✓	✓	✓
Jones et al., 2017	✓	✓	✓	✓	✓	~	✓	✓	✓
Gaydos et al., 2019	✓	✓	✓	✓	✓	✓	✓	✓	✓

Note. All studies above were considered valuable. ✓ = Met criteria. ~ = Partially. ? = Unclear. X = Did not meet criteria or was not discussed.

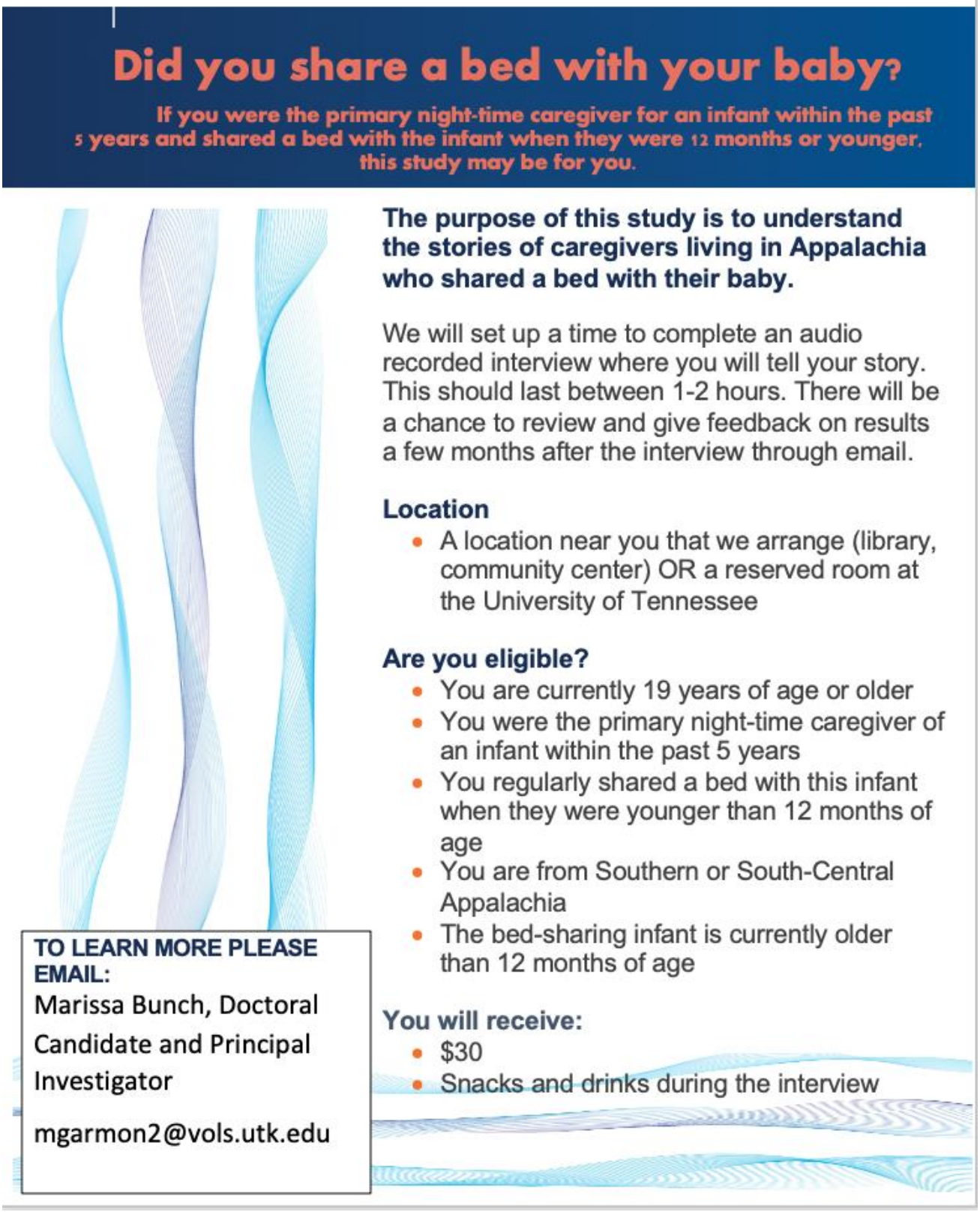


Figure A.3: Research flyer posted on Facebook

SAFE INFANT SLEEP GUIDELINES

The American Academy of Pediatrics recommends that babies sleep on a separate surface, but within arm' s reach of a caregiver. This handout gives information about preparing a safe sleep space for the first 12 months of life.

All babies under 12 months of age should sleep:

- On their backs for every sleep
- On firm, clean surfaces (Babies should never sleep on chairs, couches, waterbeds, bean bags, or any other soft surface)
- In the presence of a committed, sober caregiver
- In a cool room, dressed with no more than 1 layer more than you
- Bed or crib frames should have no gaps between the mattress and frame

Keep in mind:

- The risk of death during sleep increases if the baby was exposed to smoke while in the womb or is exposed to second-hand smoke after birth
- Breastfeeding reduces the risk of infant death during sleep
- Use of a pacifier has been linked with reduced risk of death during sleep
- Premature babies are at higher risk of sleep-related death

The American Academy of Pediatrics does not recommend sleeping in the same bed as your baby in any circumstance; If you choose to share a bed with your baby, the following situations constitute the safest possible situation:

- With a breastfeeding mother adjacent to the baby
- No exposure to second-hand smoke (smoking parents should never sleep with babies)
- Both caregivers agree not to sleep with the baby when under the influence of illicit or legal sedating drugs or alcohol
- Without other children, pets, or other individuals in the bed
- On a firm mattress with no gaps between bed frame and mattress or with no bed frame at all
- Without any comforters and no pillows near the baby
  (Bed-sharing parents should dress warmly enough to sleep without blankets or comforters and position their pillow above the baby' s head, if used at all)
- Caregivers with long hair should tie the hair back
- Extremely obese individuals should not sleep with babies

Figure A.4. Safe sleep handout given to participants.

Appendix B

Codebook for bed-sharing qualitative meta-synthesis

All excerpts should be coded with every code that applies, according to the definitions. Sub-codes are automatically assigned the associated parent code. The following codes refer to bed-sharing specifically. The excerpt must be discussing bed-sharing (not room-sharing or other topics) to be coded.

INTERPERSONAL NEGOTIATION
The ways individuals dealt with the real or perceived opinions of other people (individuals or groups) about their bed-sharing behavior.

Concealment
The act of hiding something- excerpts that discussed keeping information from or actively lying about sleeping arrangements in order to avoid conflict or disapproval.

Partner considerations
These excerpts referred to the process of deciding where the baby would sleep and how the baby would sleep when there was a discussion about a co-guardian.

Seeking support
When participants mentioned actively finding others with their same ideas and practices, whether that was family or friends.

Tradition
Excerpts referred to family traditions as reasons for bed-sharing or comments about cultural tradition or folk stories.

PRACTICALITY
The quality of being effective, useful, or suitable for a particular purpose or situation.

Adjusting to reality
Any time a participant actually mentioned that they did not plan on sharing a bed or tried repeatedly not to share a bed but ended up bed-sharing anyway. This code should not be used to infer that they were adjusting to reality, but only when the person actually stated that they planned one thing, but reality demanded something different.

Breastfeeding
Any time a participant discussed breastfeeding in the context of bed-sharing.

Context
The socioeconomic, demographic, community, home, and micro environments that influenced sleep space decisions. When guardians made reference to changes in family dynamics and partner status affecting where the baby slept, this code was used. In contrast, when they discussed their partners in ways that did not concern the actual structure of the relationship, the code was "partner considerations."

Sleep
When participants mentioned bed-sharing in order to get more or better quality sleep, either for themselves or for the baby

RESPONSIVENESS
The quality of reacting quickly and positively with interest and enthusiasm.

Instinct
Any time the participant used the word "instinct" or "natural" or strongly referred to this concept.

Safety
This code was used specifically for excerpts relating how guardians felt they could easily attend to the infant's physical needs when bed-sharing. They felt the baby was safer when bed-sharing, especially if the baby was sick.

Emotion
Responding to infants' emotional cues (crying, restlessness, perceived desire for closeness). Also referred to guardian's emotional security, feelings, and references to parenting philosophies that place bonding, love, and comfort as central.

Breaking tradition by bed-sharing
Excerpts referred to a guardian's attempt to turn away from family or cultural traditions through bed-sharing in an attempt to reach a different outcome for their child (more or less autonomy, security, etc.) than what they experienced.

Reducing risks of bed-sharing
Methods used by guardians to attempt to reduce the risks of bed-sharing, whether they would be considered effective by experts or not.

Appendix C

Sample quotations for each theme and sub-theme

Responsiveness: Emotion

From McKenna & Volpe, 2007:

"I work in an office all day long; co-sleeping is a means to reconnect."

"I will not change that co-sleeping relationship for anything in the world!!! It was the most wonderful sight to wake up to my children, lying there in our arms, smiling peacefully at us, or playfully tugging our hair."

"the fact that she could nurse when she was with me and sleep with me gave her a certain stability of personality and an experience of peace in life that I know she would not have had if we hadn't shared a bed."

From Ball, Hooker, & Kelly, 2000

One father rhapsodized about the pleasure of waking to be greeted by his infant's happy smile.

From Tully, Holditch-Davis, & Brandon, 2015

Women in the late preterm and term groups offered similar reasons for bed sharing, with nighttime infant fussiness being the primary factor.

From Joyner, et al., 2010:

I try to [put him in the crib], but it's like it's a part of me missing, and I can't let him sleep in there.

From Jones et al., 2017:

"I just don't have the strength to leave her, I'm just like no, especially when they start crying hard out. But nah I can't do it. (Nadia)"

From Abel et al., 2001:

Bedsharing…was perceived to have many practical, psychological and spiritual benefits for the baby… it was beneficial psychologically and spiritually in that the baby received love, comfort and moral and spiritual strength by sleeping with its mother.

From Chianese et al., 2009:

Parents described bed sharing as addressing their own emotional and comfort needs as well as those of the infant. Parents described feelings of pleasure, closeness, comfort, and security when bed sharing. They discussed the enjoyment they experience from being with their babies during waking hours and described bed sharing as a continuation of that pleasure: "It's your baby. You cherish it. And it feels good being beside your baby like that."

From Culver, 2008:

Nearly all of the interviewed mothers felt as though bed sharing, in some way, helped them meet the emotional or psychological needs of their child.

The words chosen by the mothers during the interviews included: "closeness", "attached", and "trust", "security and love, confidence", "calm". Other mothers also commented that they "didn't want the baby to be lonely in another room".

"How much do you think your baby loves that you are right there all night, every night!" She felt as though the baby was happier because all his needs were readily met, including the emotional need for physical closeness to the mother.

He loves that touch and I like that touch. I have always been a touchy person. And, I don't find anything wrong with it… I feel very close with my son. He knows that I am there for him. He knows that mommy is there… I feel it will make him even more of a lovey-dovey person when he gets older maybe. You know maybe he will be more, not really intimate, but more touchy and cuddly with a wife or a girlfriend. You know, or even more touchy with his own children.. .with somebody else that he will be affectionate… I want him to be a strong sensitive man. And maybe this might help him.

I think is just so wonderful of an experience, I wake up sometimes in the middle of the night and look over at her and I am like – oh my gosh, she is so precious. It is such a special time that I get to sleep with her.

Another commonality among this group of mothers was their reported inability to tolerate their child's crying. Many of the mothers said they could not place a child in the crib or bassinet if the child was crying. Some of the mothers admitted trying the "cry it out" method of getting their children to fall asleep on their own, but they just couldn't bear hearing the crying.

From Bailey, 2016:

the mothers' language when asked if they enjoyed bedsharing was quite lyrical. The mothers' expressed their passion and love for the practice: 'I'm very passionate about co-sleeping, I really love it' (Participant B); 'When they were really little I loved it, so much easier, and they are so tiny and precious and they smell so good' (Participant C); 'Oh, it's really warm and you just get

this lovely little bond with your baby and there's nothing like waking up to a tiny child in the morning, little smiles and giggles, arms around your neck for a cuddle'(Participant F).

From Ball, 2002

Baby was unsettled, brought into bed, cuddled. (Family 361) [from diary entry]

19 January, 100 days
Woke early, generally irritable, rocked in bed with mum. [from diary entry]

From an excerpt discussing the transition of a child out of the parent's bed (Abbott, 1992):

The final category, "deserted," was reserved for those responses that indicated the most intense levels of distress, including statements that the women felt deserted, and other comments like "I try to sneak him back with me whenever I can," related by a woman who had to move her child out when she remarried.

Responsiveness: Safety

I truly believe that having my baby in my bed that night may have saved her life, because if she were in a crib I wouldn't have known that she felt cold, and I wouldn't have tried to rouse her. I also believe that because we practice attachment parenting and because we are so in-tune with one another that it was my intuition that woke me up that night and made me check on my sleeping infant.

From Gaydos et al., 2015

''They tell you not to put the baby in the bed, but it feels more safe to have the baby next to you.'' Mother

From Joyner et al., 2010

Conversely, mothers who decided to bedshare often believed it to be safer because they could best monitor the infant when they were sleeping together. Some mothers were concerned about crib death and felt that bed-sharing would prevent that. Some mothers also complained that they could not adequately see the infant in the crib. Several mothers bedshared specifically to monitor the infant because s/he slept in the prone position, as they recognized that to be a risk factor for SIDS.

Most mothers stated that they were always aware of their infant's presence, even while they were asleep, and that bedsharing was the safest option because it allowed constant monitoring.

From Jones et al., 2017

Some parents referred to safety concerns associated with sleeping separately to their baby, as they felt that they would not be able to hear or respond if anything were to happen during the night.

From Hooker, Ball, & Kelly, 2001

One father spoke of his anxiety for his unborn infant. He attributed this anxiety to the fact that one of his family members had suffered a cot death, and he said that he would keep his baby very close during the night. He also felt that this need to keep his baby close was instinctive, a feeling that was reiterated by other parents.

From Ball, Hooker, & Kelly, 1999

Some parents were comfortable with the idea of falling asleep with their babies, and one young father (age 19) commented that if he ever had to take care of the baby by himself at night he "would definitely feel safer if the baby was in the bed" with him.

From Abel et al., 2001

Some Pacific-raised Tongan and Samoan caregivers saw bedsharing as protective of sudden infant death syndrome (SIDS) because the mother was able to easily sense if anything was wrong with the baby. Conversely, having the baby in a separate room was perceived to place it at risk because it could not be observed.

The thing about having different rooms for them and the parents, well, I believe this is the reason why some babies are found dead in their beds. They are too young and vulnerable. They might turn and lie on their stomach and cover their noses for too long and stop breathing. And the mother cannot see it because she is sleeping in another room.
(Samoan-raised mother of three)

From Chianese et al., 2009

Many parents expressed their belief that bed sharing is protective against SIDS because the parents would immediately know if the baby stopped breathing. Caregivers acknowledged they were not sure how they would know because they would be asleep, but they asserted a strong belief that they would be more likely to identify a lapse in breathing and would wake up if they were physically close to the baby. One person confirmed, "There's always that thing, too, with the sudden infant death thing where…you want her by you so you can always be conscious and aware they're right beside you until they can get out of that range, that danger zone, you know."

From Culver, 2008

And then in daycare he was always sick. He got real sick all the time. Sinus infections, regular colds, diarrhea, throwing up, whatever—he had it… .so to make sure that he was always okay, I put him with me. If he throws up in the middle of the night and I don't hear him, I am right here,

I will feel something, I will hear him, I will feel him move, because he always slept so close.

All of the mothers interviewed were aware of SIDS and were particularly worried about their babies' breathing. Many of the mothers described the bed sharing arrangement as "comforting" or "reassuring", which provided them with "security" of knowing their children were safe.

Many mothers reported having audio monitors and surveillance monitors specifically for listening to and watching their children during sleep. None of the mothers found these devices provided adequate reassurance of the child's well-being. They still got out of bed to verify that their child was breathing and alright. Mothers trusted their own sense of knowing the child was safe more than the security afforded by the methods provided by technology.

From Bailey, 2016

The mothers talked about feeling safer with their children closer to them: 'because I know that I wake up really easily and quickly with the slightest little movement or slightest something that's not quite right'

From Ball, 2002

Parents subjectively felt that their baby was 'safer' in close contact with them during the night than isolated in a cot—they were reassured by the ease with which they could hear or feel their infant breathing, monitor his/her temperature, or simply confirm his/ her presence, especially when the baby was ill.

From Shimizu, Park, & Greenfield, 2014

Arisa expresses the value of security engendered by being close to her child, as well as her practice of sleeping in the same bed with her child:
I needed to be close to my baby when [he/she] was little because [he/she] frequently threw up milk. I couldn't sleep, worrying if [he/she] would die from clogged milk. I haven't even thought about having [him/her] sleep in a separate room.

Responsiveness: Instinct

From McKenna & Volpe, 2007

Long story short, we bring him home at 10 days old after countless procedures, never having given any thought to our child sleeping anywhere but in his crib and then a funny thing happened my strongest maternal instinct was telling me to bring him to bed with us.

This sort of research is important in our society, but ridiculous overall. Why should you or anyone have to spend time, money, and effort to prove what has been proven in the biggest lab of all, namely 300; 000þ of mothers and babies? It is like doing research to prove that wheels are

round and roll downhill. . .

From Dodd & Jackiewicz, 2015

They all agreed that ‘the child comes first’ and that not to bed-share with their infants was ‘unnatural’.

From Jones et al., 2017

I’ve got Pakeha friends and stuff, the way that she does it, she’s more to the book, you feed them, you put them down if their bum’s changed, they’re fed, and they’re still crying then just let them cry, whereas I can’t do that it’s just didn’t feel right to me kind of thing, but it’s a big thing, especially coming from a big family as well, I can’t really just do something that doesn’t feel right. (Tina)

From Ball, Hooker, & Kelly, 1999

most new parents claimed to have trusted their instincts: “it was a natural decision,” “it feels like the right thing to do,” “feels comfortable,” “more convenient.”

From Hooker, Ball, & Kelly, 2001

One father spoke of his anxiety for his unborn infant. He attributed this anxiety to the fact that one of his family members had suffered a cot death, and he said that he would keep his baby very close during the night. He also felt that this need to keep his baby close was instinctive, a feeling that was reiterated by other parents.

From Culver, 2008

For many of the interviewed mothers, following their maternal instincts to bed share was difficult; however, the result of doing what worked for them, what was right for them and their family often resulted in increased maternal confidence.

Form Caraballo et al., 2016

Above all, mothers across all sites consistently felt that their instinct trumped advice from any source. One mother shared, “I’ll get different information from my mom and doctor, and then. Whatever I feel is right, I’ll go on.” Regarding physician advice, one mother stated, “Sometimes you just don’t listen to their stuff. You—obviously you know what’s right and what’s not right.” This was particularly true with bedsharing; several mothers acknowledged being informed about the risks but still described an instinct that it is better to have the baby in their bed for close observation.

From Bailey, 2016

Other mothers described only needing a very slight rousing for them to attach the child or that their 'maternal instincts' meant that they were easily able to pick up information that the infant may be sending at night, before the infant had reached the stage of crying out and getting upset.

Practicality: Sleep

From McKenna & Volpe, 2007

I know that we have been much better rested than most of our peers with similar aged children.

From Dodd & Jackiewicz, 2015

Infant bed-sharing doesn't destroy the marital relationship – sleep deprivation does though! You can always put your kids in their own beds, have time with your husband and then they come in. There are ways around if you have the resources, sleep with your husband for the first few hours then sleep with the baby in a guestroom on a bed.

I also was so tired that I couldn't fight about it all the time, I really feel as though the crashing fatigue I experienced and this issue took away from my mothering experience.

From Joyner, et al., 2010

out any- time soon, because she doesn't sleep through the night. I'm breastfeeding, and her room is on the other end of the hall, so I'm just like, why do I have to keep getting up? You know? And she still feeds maybe every 2 to 3 hours, she doesn't feed, you know, every 4 hours or anything like that, so it's more convenient for her to be right there in the bed.
He sleeps in his crib, but most of the time I put him in the bed with me. I like the bed because I really don't have to get up. I just give him the bottle and go back to sleep, so I don't have to get up.

From Jones et al., 2017

Parents who using parent-assisted approaches to infant sleep found the struggle of having to get up frequently throughout the night to be tiresome and, therefore, would often relocate their babies into their own bed later in the night.

From Hooker, Ball, & Kelly, 2001

"More cosleeping has occurred than I ever would have expected," commented one first-time mother. "I felt that I was barely functioning for the first six weeks. I was so tired, and in desperation I kept the baby in bed with me after a feed. Yes, I was very nervous about it, but after the first time I began to relax and could actually get some sleep. My husband was much more relaxed about the baby being in the bed."

From Chianese et al., 2009

"She sleeps longer when she sleeps in the bed [with me]." Parents then correlated improved infant sleeping—longer durations and more peaceful sleeping—with their own ability to obtain restful sleep. As one parent declared, "I get a longer amount of sleep when she's in the bed with me."

From Culver, 2008

Many of the mothers reported that their babies experienced a deeper sleep or
longer sleep when bed sharing. The positions most often described for sleeping were with the child prone on the mother's chest or with the child supine nestled in the crook of her arm or near her axilla.

One single mother who was working full time and also attending college admitted
But it is just hard when you are doing it on your own, and you need to get as much sleep as you can. You try to do whatever you can to get that, even if it is an extra five minutes.

The amount of sleep mothers get is important for several different reasons. It can influence maternal mood and job performance. A mother with two boys reported,
I was much happier because I was getting sleep… I don't feel like I sleep differently. I have always said, even since my first son was a baby, I have always told people, you may want to shoot me but I never felt like a sleep-deprived mother because I got my sleep with the baby in the bed… even though I'm awake a couple of times during the night, I still get up feeling rested because I wasn't awake, awake, having to get out of bed, walk down a hall, go into another bedroom and sit in a chair, whatever you do. I don't have to do all that, and I am not that awake.

From Bailey, 2016

One mother
described her sleep before she started bedsharing as: 'constant waking, and having to get back to sleep, and you just get back to sleep and you've got to wake up again'

From Abbott, 1992

"we couldn't get any sleep and we both work and need our sleep,"

Practicality: Context

From McKenna & Volpe, 2007

An additional category of parents who felt that co-sleeping served as a critical means of protecting their children, in some cases a potentially life-saving arrangement, involved families

with either deaf parents or deaf children.

From Tully, Holditch-Davis, & Brandon, 2015

One mother of a late preterm infant reported that she would initially bed share because she did not have the opportunity to purchase a bassinet due to the early timing of childbirth. A mother of a term infant reported that she would have her infant sleep in a bassinet at home but that she had not obtained one yet. At 1 month, this woman said that they had bed shared throughout the first postpartum month.

From Dodd & Jackiewicz, 2015

There was also general agreement that larger families, lack of appropriate housing and the socio-economic circumstances for many Aboriginal families meant that infant bed-sharing was inevitable. Two of the women viewed this as even more likely in rural areas.

From Joyner et al., 2010

Yea, my baby sleep in the bed with me, too. The only rea- son why is because I don't have room where I'm at. So it's like, I got to make room, so she sleep in the bed with me.

From Ball, Hooker, & Kelly, 1999

One new father, whose wife had to return to hospital due to persistent bleeding after five weeks, coped with the nighttime care of his daughter by having her in bed.

From Hooker, Ball, & Kelly, 2001

In a few cases, circumstances such as lack of bedroom space determined where a baby would sleep after the initial period.

From Abel et al., 2001

Some parents varied their baby's sleeping arrangements according to changes in their living arrangement or relationship status, for example, bringing the baby into their bed in the case of a relationship separation.

From Culver, 2008

That is also, you know, because she does not have another parent, is especially why I wanted to really try to bond with her and make her feel secure, because you know you read everything about how they say they get their sense of, or their confidence from their father. So, I try to do everything right. I try to bring her up good.. .It's what the baby needs. I feel if you want to bring them up right, they need their mom for the security, the love.

One mother who gave birth by cesarean section was influenced by the incisional pain she experienced each time she needed to get up out of bed for her daughter's nighttime feedings. That was another reason like she would sleep in the bed with me, just because it was really painful trying to get in and out of bed for about a week afterwards. I think it was probably, you know, just because I was in so much pain still from the cesarean. And just, again, the convenience because of nursing, she was up, actually, every three hours, on the hour.

You were hearing the shootings all of the time right after my son was born.. .It was nerve wracking and I wanted self defense classes and I debated about (getting) a weapon.. .If I heard somebody come up those stairs, or touch those stairs, they had to go through me before they could get to him (son)…So it was nice because I knew he was safe.

From Bailey, 2016

Of the families where being alert to drive was a priority, one of the partners was described as a heavy sleeper who would not be woken by the infant at night. He would, though, be disturbed if the mother was distressed from broken sleep. 'He never woke; if I woke five times a night with [the baby], he wouldn't notice… but he is woken by me if I'm grumpy, so co-sleeping was much better'

From Ball, 2002

In one young family we interviewed bed-sharing was not so much a matter of choice, as of circumstance. The parents were a teenage couple (mother 17, father 19) awaiting housing provision from the local council. In the meantime they were living with relatives, where they were provided with a single bed. Following the birth of their baby all three members of the family slept together in the single bed—baby in the crook of his mother's arm squeezed between both parents.

From Abbott, 1992

a change that is stimulated by a mother's desire to reduce some undesirable irritant in her interaction with her child (e.g., alleviating crowded sleeping conditions in her bed so she can get some sleep), or a change that is motivated by the birth of a new child who will replace the one who is being moved out or by the death or divorce of a husband that results in a child being moved in to fill a now empty space, is typically experienced as positive change,

Practicality: Sleep

From McKenna & Volpe, 2007

He had yet to latch on and breastfeed which caused me to pump to maintain my supply of breastmilk. We worked with numerous lactation consultants and various alternative feeding

methods to no avail. I am convinced that the constant skin to skin contact experienced through sharing sleep helped in eventually getting Dylan to latch on.

From Jones et al., 2017

My kids always fell asleep on the breast pretty much, I still breastfeed him every now and then now, sometimes he'll fall asleep like that if he's really exhausted. (Waiora)

From Hooker, Ball, & Kelly, 2001

Many of the mothers involved found that they could feed lying down and, therefore, found bedsharing an easy option. Indeed, 10 mothers began bedsharing in hospital because it facilitated feeding. One first-time mother explained how she continued bedsharing at home after leaving hospital. She stated that, as she became more proficient at breast-feeding, when feeding through the night she felt that she was not actually fully awake but, rather, was in a "restful, half awake/half asleep state."

From Chianese et al., 2009

Nursing mothers believed that bed sharing made breast-feeding convenient. One mother explained, "I'm breast-feeding and to roll over and just to do it without getting up, getting her, anything else."

From Culver, 2008

"It is easy, too, at night to feed and stuff… I used to breastfeed my baby. So, it was easy.. .just lift, feed, done, to sleep! They would sleep right there, you don't have to pick them up, put them down, get them around, you know?" A second mother echoed those thoughts, "You know, you roll over, you nurse. It is all a much quieter experience."

From Bailey, 2016

The mothers felt that the breastfeeding experience when bedsharing was strongly enhanced and that breastfeeding and bedsharing were clearly inter-related. Some mothers felt that bedsharing had positively influenced the duration of breastfeeding: 7 think it's … contributed to why I'm still breastfeeding' (Participant A). This mother described feeding her children far longer than she had expected to, which she attributed to bedsharing.

From Ball, 2002

The most common reason given by mothers in our sample for sleeping with their infants was the ease and convenience of night-time breastfeeding when bed-sharing.

Practicality: Adjusting to reality

From McKenna & Volpe, 2007

numerous parents explained that, in spite of a planned decision to have their infant sleep in a crib, the ease of nighttime breastfeeding and the emotional security that ensued made co-sleeping in the form of bedsharing the most beneficial and practical arrangement.

From Hooker, Ball, & Kelly, 2001

"More cosleeping has occurred than I ever would have expected," commented one first-time mother. "I felt that I was barely functioning for the first six weeks. I was so tired, and in desperation I kept the baby in bed with me after a feed. Yes, I was very nervous about it, but after the first time I began to relax and could actually get some sleep. My husband was much more relaxed about the baby being in the bed."

From Culver, 2008

Well with my first daughter I was reluctant. You know I fought it for the longest time. I kept trying the crib, and trying the crib and trying the bassinet, and you know, and then people tell you that your child should not sleep with you, and…1 just spent the whole time worrying about what other people thought. Self-doubt about the decision to bed share was common among the first time mothers. They seemed to lack the confidence and perspective that comes from experience in parenting.

From Bailey, 2016

After the birth of her first child, the mother described the midwives saying: 'don't fall asleep with him in bed with you …it is really dangerous,' which is why I came home thinking it's a really dangerous thing to be doing' (Participant A). This mother described how this thinking was at odds with the reality that the baby was actually bed-sharing a considerable amount of the time. 'In my head he was in his own bed and the exception was that he would fall asleep in bed with us' (Participant A).

Approval: Seeking support

From Culver, 2008

One mother described her experience using an online chat forum so she didn't have to feel "like you were alone".
I would not say that they gave me information…It was kind of like approval. Like we were doing the same thing. It is not like you are this outcast because a lot of people look at you like, "You sleep with your kids?

From Bailey, 2016

in general, the mothers built communities of friends and other mothers who had similar parenting styles and supported their practice. Often these communities were associated with the ABA groups, where mothers could attend discussion meetings and form friendships with other mothers interested in breastfeeding. One mother described deliberately moving to an area that had a high concentration of like-minded people. ‘So it became apparent when I was pregnant that I needed people I could connect with, and I did that first online’ (Participant B). These online contacts encouraged the mother to connect to others in person. ‘They were mothers and they knew the importance of community when you are doing it outside the box’ (Participant B). Another mother described her support base for her parenting choices: ‘I’ve got a lot of friends who do the same as I do and a lot of support through that, where it’s pretty normal, that’s how my friends and I do things’ (Participant E],

Approval: Partner considerations

From Ball, Hooker, & Kelly, 2000

fathers in this sample, did not appear to consider their co-sleeping infants to be intruders in the marital bed.

From Dodd & Jackiewicz, 2015

This participant referred to the ‘safe-sleeper’ aids that can be used in the parental bed, claiming that if one had been approved officially, she would have felt more comfortable using one of these. She reflected this would have been a good compromise for her and her husband and would have prevented a lot of arguing and stress in the relationship.

I’m against infant bed-sharing and I really did have a worry with her [baby’s] dad – he is an ‘involved father’. There are plusses and minuses to this. He used a traditional African carry sac to walk baby around with (close to body) because he had heard about how Western mothers ‘separate’ children and he didn’t like it. I really used to worry because sometimes he would walk around the house with baby like this [in the sac] and then once he and baby were tired would lie down on the couch. I would be frantic and have to get up to make sure my daughter was okay. Dads can sometimes think they know so much more. It was hard because I felt grateful that he was doing his bit, but I was also worried about the baby being rolled over on. I also was so tired that I couldn’t fight about it all the time, I really feel as though the crashing fatigue I experienced and this issue took away from my mothering experience.

From Ball, Hooker, & Kelly, 1999

In general, however, the experienced fathers were happy to have their babies both in their bedroom and in their bed. In one instance (the cosleeping twins) the mother had a previous child with whom she had coslept, but for the father these were his first offspring. Although he soon adjusted to having the babies sleep in the bed (alternating one asleep on his chest and one by the

mother's side), for the first week he described sleeping with "one foot firmly planted on the floor" for fear of rolling on them.

From Hooker, Ball, & Kelly, 2001

This mother also thought that "cosleeping will be more convenient for breastfeeding but I can imagine that there will be times when my partner sleeps elsewhere when I've got the baby in bed."

From Abel et al., 2001

In Pacific-raised families it was relatively common for the husband to sleep elsewhere for the first few weeks.

From Culver, 2008]

Everything else is second and so for him part of co-sleeping was placing that child as the center of your existence. The child goes between the parents and they are the center and this was such a shock to me, this is a difference that I didn't know and I was alarmed because I am one often children, I'm from a big family, I thought I was from a typically kinda loving big family, kinda of group and the idea of co-sleeping was, I don't know, I have many sisters and many nephews and nieces, but no one has done this and I've never had any exposure or experience with this

From Bailey, 2016

Another mother, who had a non-Western partner, experienced strong support for bedsharing from him as this had been a common practice in his culture.

From Shimizu, Park, & Greenfield, 2014

On a different forum, Izumi commented:
Males always say, 'I would be sleep deprived by the baby's night crying.' I was upset, thinking why he said that as if he were a third person. This is our baby. So, I let him [forced him to] sleep together with us. Even though the baby cried, he has never awakened. I immediately wake up"
Sleeping arrangements for these women are not about the baby and her psychological development, but about adult gender roles.

From Abbott, 1992

They talked about it as "I sleep with my child," or as one 40-year-old mother of seven said, "I never slept away from my babies when they're little, never slept alone." Even though most were also sharing their bed with their husband, no mother ever said, "we sleep with the baby." Among the married women, only five reported their husband to sleep somewhere else in the house. The mothers apparently conceive of co-sleeping as a two- person event, an interaction between

themselves and their child, de- spite the presence of a third party.

Approval: Tradition

From McKenna & Volpe, 2007

one mother did an investigation on her own:
I found that the ban on co-sleeping came from several sources: doctors practicing around the turn of the 20th century having read Freud and the Oedipus complex theory and wishing to prevent the conditions for it; these same doctors' attempts to lower contagion to infants . . . and the behaviorists of the 30's who thought all 187ehavior was conditioned and advised parents to regulate everything. These movements produced what I call 'intellectual incest': one authority quotes a previous authority who quotes a previous authority until something becomes the collective wisdom, without it ever being based on proper research.

From Gaydos et al., 2015

While we observed examples of culture and family influencing all aspects of childrearing during our focus groups, providers were more likely to suggest that family advice supersedes clinical advice and to express limited ability to address this issue beyond providing the standard AAP recommendations.

From Dodd & Jackiewicz, 2015

In contrast to the non-Aboriginal women interviewed for the study, the Aboriginal women were much more likely to explain that they would listen to their own mothers, aunties, sisters and grandmothers about how to care for their baby, rather than their partners or health professionals.

From Jones et al., 2017

Think for me a lot like I know with being Māori it's a lot about the kids and making sure that they're loved, giving them everything, for me I've got Pakeha friends and stuff, the way that she does it, she's more to the book, you feed them, you put them down if their bum's changed, they're fed, and they're still crying then just let them cry, whereas I can't do that it's just didn't feel right to me kind of thing, but it's a big thing, especially coming from a big family as well, I can't really just do something that doesn't feel right. (Tina)

From Abel et al., 2001

One] concern is with the fact that nowadays mothers tend to let their babies sleep on their own, in their own little cot or bed. There is a Tongan belief that there is such a thing that we call kaliloa, when the mother opens her arms and continuously holds the baby close to her most of the time. We believe that this is the best way of bringing up any child and this is their rightful place.

(Tongan-raised grandfather)

From Chianese et al., 2009

Parents consistently identified a tradition of bed sharing with their own parents and with previous children as an explanation for their choice to bed share with their baby. One mother's response to the question about the decision to share a bed was, "Well, I still sleep with my grandma." Along those lines, they identified the habitual nature of the practice and the comfort in knowing that one's ancestors did it this way as well. One parent asserted, "It's like tradition to sleep with mother."

From Culver, 2008

Another theme, related to culture, but slightly different was that there was a history of bed sharing in the family; thus, bed sharing was viewed by many of the interviewed mothers as normative behavior. Many mothers recalled intergenerational bed sharing with their own mothers, grandmothers, or sisters as children.

From Bailey, 2016

One mother described the comfort she felt with bedsharing at her parents' place, as bedsharing had been the normal cultural practice in her own childhood. This mother had a relatively low level of support for the practice amongst her immediate friends and would sometimes conceal the practice from them if she didn't feel like 'arguing the point'.

Approval: Concealment

From Hooker, Ball, & Kelly, 2001

Follow-up interviews at three months also revealed a parental tendency to engage in "covert bedsharing." Such statements as "I wouldn't tell the midwife or health visitor, but he usually sleeps in bed with us" were common. Some parents were so unsure of the reaction they would face that they admitted lying about bedsharing to their own mothers and mothers-in-law. One bedsharing mother recalled her anxiety during the community midwife's postpartum visits, her nervousness around possibly being asked about sleeping arrangements for the baby, and her relief that the subject was never mentioned. Another mother commented: "We have taken to lying to anyone who inquires about our arrangement, with the exception of a few trusting friends and my mother who don't use the opportunity to criticize our decision."

From Culver, 2008

A 33- year old mother said, "People of my generation made me feel like it was okay to do it, and people of my parents' generation made me feel like that isn't something we do…so we kind of just don't talk about it with them."

From Bailey, 2016

The mothers felt that they were under surveillance by MCH nurses during the initial home visit: ‘They come to your house to see where your baby is going to be sleeping to make sure it is safe, you know, so there’s this underlying assumption that anything you do other than what’s in the [SIDS] brochure is unsafe’ (Participant A}. Three of the mothers mentioned that they had arranged the infant’s bed set-up so that it looked like they were not bed-sharing: ‘The first visit for both [children], I had the cot set up, as if I was going to put the child in there … perfectly set up according to the guidelines with the little sheet at the bottom tucked in!’ (Participant F). The mothers tended to not discuss bedsharing during visits with the nurses, although one mother said that she would discuss it if she felt that the particular nurse was sympathetic.

Appendix D

Question Pro Survey: Do you qualify for this caregiver-infant bed-sharing study?
bedsharing.questionpro.com

Hello. Thank you for your interest in this research study.

My name is Marissa Bunch and I am a PhD student in Nursing at the University of Tennessee. The purpose of this research study is to understand the experience of caregivers from Appalachia who have shared a bed with their baby by studying their stories. If you are interested and qualify for the study, I will ask you to meet with me to do a face-to-face interview where you will tell your story of bed-sharing with your baby. This interview will be audio recorded and you will have the option of reviewing some of the results a few months after the interview. You will receive $30 cash after signing the informed consent and can keep the money even if you decide not to continue with the study.

If you still think you might be interested in participating in the study, please answer the following questions to determine if you are eligible. This could take up to 15 minutes of your time. There are no foreseeable risks associated with this screening survey. However, if you feel uncomfortable answering any of these questions, you can withdraw from the survey at any time. I will keep all the information I receive from you confidential.

If you have questions at any time about the survey or the procedures, you may contact Marissa Bunch by email at mgarmon2@vols.utk.edu. Thank you very much for your time and support. Please start with the survey now by clicking on the Next button below.

Are you currently 19 years of age or older? *Yes / No*

Were you the primary night-time caregiver of an infant sometime within the past 5 years? *Yes / No*

Did you share a bed with the infant when they were younger than 12 months? *Yes / No*

Do you think you shared a bed with the infant at least 4 hours every night, 5 days every week for one month of the infant's first 12 months of life? It is okay if you don't remember exactly. Just answer with your best guess. *Yes / No*

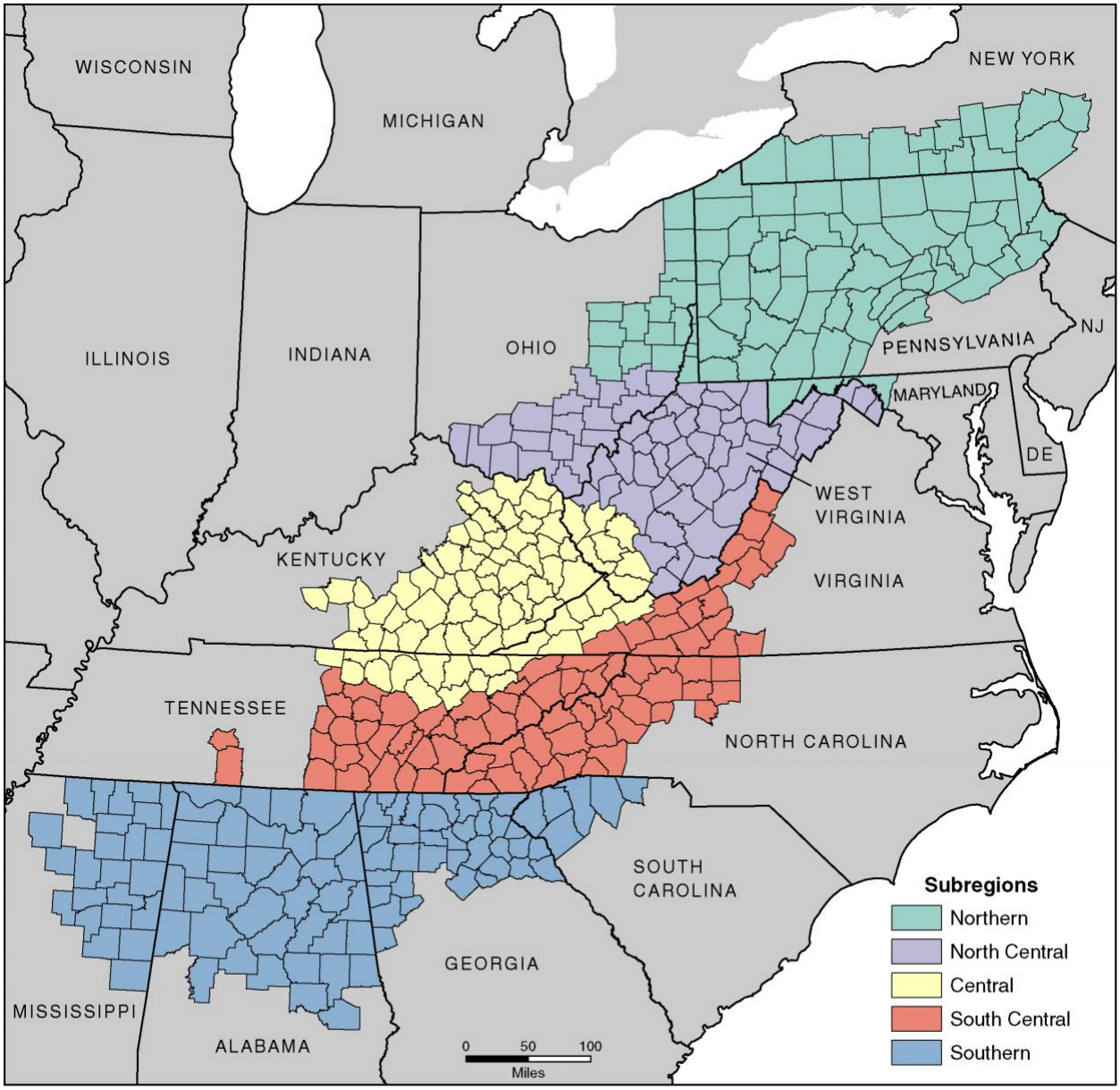
Is the child you shared a bed with currently older than 12 months of age? *Yes / No*

Are you currently sharing a bed with any infant under 12 months of age? *Yes / No*

In which of the following states do you currently live?

Alabama, Georgia, Mississippi, North Carolina, Tennessee, Virginia, Other

You have indicated you live in a state located in Southern or South-Central Appalachia. In the map below, the orange and blue areas show Southern and South-Central Appalachian areas of these states. Do you currently live in one of these areas?



Map by: Appalachian Regional Commission, November 2009.

Yes / No / I'm not sure

VITA

Marissa Bunch received her Master of Science in Nursing at Vanderbilt University in 2008 and was certified as a Primary Care Pediatric Nurse Practitioner in 2008. She worked as a pediatric nurse practitioner for 12 years in Cleveland and Chattanooga, TN and has experience in newborn nursery, acute care, and urgent care. Marissa is interested in exploring ways to support families and reduce adverse childhood experiences, bolster resilience, and optimize development. She is also interested in the use of narrative to understand human experience and restructure lives. Marissa has discovered her ultimate passion through teaching undergraduate and graduate pediatric nursing students for four years at the University of Tennessee at Chattanooga. She is a fellow in the National Association of Pediatric Nurse Practitioners (NAPNAP) and member of the Childbirth and Postpartum Association (CAPPA), Society of Pediatric Nurses (SPN), National Association of Neonatal Nurses (NANN), Tennessee Nurses Association (TNA), and the American Nurses Association (ANA).