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**NOW I LAY ME DOWN TO SLEEP: AN ETHNOGRAPHIC ANALYSIS OF
THE DEVELOPMENT, IMPLEMENTATION, AND SUSTAINABILITY OF A
SAFE INFANT SLEEP EDUCATION CAMPAIGN IN SPRINGFIELD, MA**

A Dissertation Presented

by

JULIE MARIE SKOGSBERGH

Submitted to the Graduate School of the
University of Massachusetts Amherst in partial fulfillment
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

May 2016

Department of Anthropology

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Approved as to style and content by:

Jean Forward, Chair

Whitney Battle-Baptiste, Member

Aline Gubrium, Member

Jackie Urla, Chair

Department of Anthropology

DEDICATION

This is dedicated to the late, Dr. Sonia Ringstrom, Professor Emeritus, Loyola University.

Thank you for always supporting my educational pursuits, for the monthly beer and pizza money as an undergrad, and for your unwavering generosity. I was able to finish writing because of you. I hope I have made you proud.

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Anyone who has gone through this process knows you do not, nor can you, do this on your own.

There are many people who have been a part of this journey with me.

To my Dissertation Committee Chair, Dr. Jean Forward, you have shown me nothing but support and encouragement throughout this entire process. You have always referred to me as a future colleague, and I cannot thank you enough for always treating me with such respect and dignity. I hope I have made you proud. As your advisee, there are no words that fully encompass the gratitude and respect I have for you. Thank you for taking me on half way through this program, and for guiding me through until the very end!

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To my parents – Ruth Henrichs and Gary Skogsbergh – thank you for your support and encouragement even though I know you were not always sure exactly what I was doing spending all these years in school. I know that I am extraordinarily lucky to have grown up in a home where you both valued and emphasized education and learning. When we were little, each week my mom would take my brother, sister, and I for a wagon ride walk uptown to our local library. Books were *always* a part of our lives. I was a typical first-born overachiever and perfectionist, but my parents never pushed me. They always just said, “try your best.” So, as long as can I remember, no matter what grade I got, or how I did in school, if I had tried my best, I was ok with the outcome. Thank you for all you have done to nurture, support, and love me unconditionally.

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And to those upon whose shoulders I stand –

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According to social media this is the year of #SquadGoals. So, to my #Squad of BFFs – Dr. Vanessa Martinez, Dana Borrelli-Murray, Lisa Galvin, and Heidi Reid – You have each been there through it ALL. Thank you for your love, support, notes of

encouragement, texts, surprise gifts, and most of all your unwavering friendship over many decades!

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Y a mi querido Melinton. No hay palabras para lo que siento por ti. Tú llegaste en mi vida y has estado una bendición. Te agradezco tanto por ponerme a reír y por ayudarme tanto. Tú apoyo, tú amistad, y tú amor me ha sostenido muchísimo. Estoy tan feliz por la vida que hemos planeado juntos. Te amo con todo que tengo para siempre. Siempre estaré a tu lado.

ABSTRACT

NOW I LAY ME DOWN TO SLEEP: AN ETHNOGRAPHIC ANALYSIS OF THE
DEVELOPMENT, IMPLEMENTATION, AND SUSTAINABILITY OF A SAFE
INFANT SLEEP EDUCATION CAMPAIGN IN SPRINGFIELD, MA

MAY 2016

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This dissertation was a collaborative, community-engaged research project with a local community-based organization, Project Baby Springfield, specifically addressing a two-year period from 2012-2013 when the organization designed, developed, and implemented a bilingual safe infant sleep education campaign in the City of Springfield, MA.

This dissertation draws upon two theoretical perspectives: Critical Medical Anthropology and Critical Race Theory. It also employs a mixed methods approach drawing upon quantitative and qualitative data including: state and citywide statistics provided by the Massachusetts Department of Public Health, anonymous safe infant sleep surveys and focus groups among parents and grandparents, individual interviews, and participant observation. Throughout each stage of the research process, I worked closely with Project Baby Springfield team members in addition to mentoring and training four undergraduate interns from different social science disciplines who were involved at

different stages of the project. In the end, the team collaboratively designed and implemented a public health intervention project in order to address safe infant sleep through a bilingual education campaign that utilized social media and direct educational outreach within the Springfield community. The project sought to highlight issues such as racism and poverty with the overall goal of decreasing the overall infant mortality rates connected to unsafe sleep through empowering women and men within their own lives as mothers, fathers, grandparents, caregivers, and community members.

This dissertation argues that one of the central reasons why parents and grandparents make certain choices about how and where their infant or grandchild will sleep are deeply rooted in the care for, concern about, and safety of the infant. This is supported in the scholarly literature, and remains significant as it stands in opposition to the racially-coded messages within the larger societal and political narrative that have constructed Black, Brown, and poor people as unfit parents. Furthermore, this dissertation argues that the racial inequity elucidated in the African-American infant death rate is directly relevant to the current social and political climate surrounding the issues of racial justice and human rights in the United States. I demonstrate that this issue aligns itself with the current Black Lives Matter movement and is an essential and necessary part of the conversation arguing that connections can then be made regarding the impact of racism on Black life not only in the womb and infancy, but throughout childhood, adolescence, and adulthood.

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CHAPTER 1

INTRODUCTION

The idea that some lives matter less is the root of all that is wrong with the world.

- Dr. Paul Farmer
(Partners in Health 2013)

Introduction

Which lives truly matter? Indeed, this question is at the heart of what I write here. As I began writing this dissertation over the past year, there has been a swirl of activity in the United States surrounding the structural violence – specifically police brutality and racism – and the detrimental and devastating impacts on communities of color across the country, particularly within the Black community. This movement, coined the #BlackLivesMatter movement is “a call to action and a response to the virulent anti-Black racism that permeates our society” (#BlackLivesMatter N.d.). I start here, as this movement not only draws attention to the context within which I am writing up my dissertation research, but also highlights the context in which my research project took place in the small urban northeast city of Springfield, MA.

The United States (U.S.), a nation founded on the principle of equality for all, has yet to fully realize that dream for all. One need only examine the range of health inequities that exist in one of the wealthiest nations in the industrialized world in order to demonstrate this fact. I intentionally use the term “health inequities” rather than disparities or inequalities here in cohort with several noted health scholars who have written extensively about the topic as it relates to social justice and health in the U.S. and around the world (Bezruchka 2010; Birn 2009; Braveman 2006; Braveman and Gruskin

2003; Carter-Pokras and Baquet 2002; Krieger 1994; Krieger et al. 2010; Navarro 2009; Therborn 2012; Whitehead 1990).

According to Whitehead (1990), the term inequity has both “a moral and ethical dimension” (5). She highlights its significance in that “It refers to differences which are unnecessary and avoidable but, in addition, are also considered unfair and unjust” (Whitehead 1990:5). This is particularly evident when looking at the high infant mortality rates (IMRs) in the U.S., and is even more so when looking at how those rates differ by race and ethnicity. Chapter 2 will provide more detailed background information on infant mortality as a whole followed by the disparate IMRs, Sudden Unexpected Infant Death (SUID), and Sudden Infant Death Syndrome (SIDS) rates consistently present between non-Hispanic, Black and non-Hispanic, White populations in the U.S.

Research Vignette – “Springfield is such a scary place”

The following are all statements I have heard while in the field as well as after when asked about what my dissertation project is about by various people throughout western Massachusetts:

“Why would you want to go there?”

“Why do you want to work there?”

“It’s so dangerous there.”

“Be careful.”

“That place is so ghetto.”

“Who would want to live there?”

“That’s a bad neighborhood.”

“That’s such a bad area.”

“Those people...”

“A place like that...”

“Springfield is such a scary place.”

Upon moving to western Massachusetts for graduate school, all I knew and heard about Springfield, MA came from what I heard on the news and by word of mouth. I would hear weekly on the local news about a drive-by shooting, gangs, gang violence, drugs, homicides, homelessness, abandoned buildings, and extreme poverty. The visual depictions almost always depicted black and brown bodies. Additionally, the language used to discuss the space and the people was racially coded, as can be noted in the above comments and statements. In fact, this is not just limited to what I have heard in the news or from others when discussing my research. This past semester, a former student of mine who is a Springfield resident in the Mason Square neighborhood, the same neighborhood where my dissertation research took place, had a similar experience. She was doing her final capstone project on the theme of home, and when she typed her address into the search engine, the first word that popped up was “ghetto.” I was sitting right next to her when this popped up on the screen, and she turned and said to me, “Look at this Julie. It says my home is in a ghetto. I guess I live in a ghetto.” My heart sank hearing her say this, and seeing the look on her face as she did is an image I cannot erase from my mind.

Nobody I encountered through my early years at the University of Massachusetts Amherst (or UMass, as it is known locally) ever talked about going to Springfield, despite the city being a mere 20 minute drive down the road. While teaching at a local state university I learned of a group in Springfield working on the topic of health disparities, so I went to the meeting with a friend and colleague with similar research interests. I remember being so surprised on that Saturday morning driving to the meeting. Some parts of the city we drove through had a city feel to them, similar to other

urban areas I have lived in or traveled through. Other parts had a neighborhood feel with large homes reminiscent of the time I lived in Somerville, just outside of Boston, MA. The houses varied in their curb appeal. There were certainly homes that were boarded up, but most were not. We saw people walking. We drove past a Puerto Rican bakery and restaurant, as well as a local *bodega* with a Dominican flag painted on the awning, and it felt like being in the Dominican Republic when visiting family. We were so excited, and I could not wait to stop and try *la comida* because we certainly had not had traditional Latin food near UMass unless we cooked it ourselves.

As we were driving, all I remember was thinking to myself, “This is not the place I have heard about or seen on the news for the past five years while living in western Massachusetts.” I felt shame and embarrassment that all I knew about this place was everything negative, and my first experience was anything but that. I tried to wrap my head around the fact that I was seeing and experiencing a different place and space than I had imagined based on what I had seen and heard about this place – Springfield, MA.

Upon arrival to the location of the meeting that brisk March morning, we were welcomed into the group by Ms. Betty Agin, a vibrant, warm, and outgoing woman in her 50s who lives in Springfield and does local community organizing on various social justice and equity issues. Betty often had several of her grandchildren with her at the monthly Saturday morning meetings on Bay Street in the Mason Square neighborhood of Springfield, so the meetings always had a relaxed and family friendly feeling and openness to them. Betty would eventually become my key gatekeeper in the field. I was able to connect with Project Baby Springfield (PBS) and other community members and groups within the Springfield community through her and the work that she was involved

in at that time. She welcomed my colleague and me to that first meeting, and we were both treated like family from day one. Betty eventually became a dear friend in addition to serving as my key gatekeeper in entering the field. We have since shared many life events beyond the community-organizing events – wedding, divorce, the death and funeral of her beloved husband, the complete loss of her home to a fire, and also many family barbeques and life celebrations. I continue to support her outreach efforts each summer for her annual CORI event as a way to honor our friendship, our working relationship on social justice issues, and as a way to stay engaged within the Springfield community. Betty was the first person I met that first day I went to Springfield, and for me, she represents so much that is good and amazing about Springfield and the people I encountered during my six years of working with the Project Baby Springfield team.

Purpose of Study

My desire to highlight injustice, to work towards justice and equity, and to make the invisible visible drew me to this work. I wanted to combine my interest in the intersections of race, racism, and health along with my ongoing commitment to social justice. Once I found my community organization, Project Baby Springfield (PBS), I was eventually able to design my dissertation research project around their identified goals and objectives, which emerged while I was a part of the team. I intentionally sought out a project that was already established within Springfield, a majority community of color. I was very conscious of not wanting to be that outsider (researcher, White woman, non-Springfield resident) coming in and pointing out what needed to be fixed, but rather wanted to be a part of a community-based and collaborative project, both of which were important factors in choosing this as my dissertation research project. This dissertation's

central focus is on the topic of safe infant sleep given that Sudden Unexpected Infant Death (SUID), which includes Sudden Infant Death Syndrome (SIDS) as well as other causes of death, including sleep-related deaths, is the leading cause of infant death nationwide among healthy infants during the post-neonatal period, age one month to one year (CDC, SIDS; Matthews and Moore 2013). This dissertation specifically explores the following research question: What are the various factors that impact the development, implementation, and sustainability of a safe infant sleep education campaign in the context of structural violence and poor health outcomes within a historically marginalized community? The outcomes of this project will be shared with PBS and its team members as well as with the key community leaders within the Mason Square neighborhood where the majority of the PBS team's efforts were focused with the hope that these findings will continue to inform the team's future efforts addressing the overall issue of infant mortality and health equity in Springfield.

Contribution of Research

While pregnancy and birth as well as reproductive rights have been written about extensively within the anthropological literature, there is little work done on infant death and infant sleep, with the exception of the extensive work by physical/biological anthropologists James McKenna, director of the Mother-Baby Behavioral Sleep Laboratory at the University of Notre Dame, that of Helen Ball, director of the Parent-Infant Sleep Lab at Durham University in the UK, and that of medical anthropologist Lane Volpe, who has held positions at both of the sleep labs noted here (Ball & Volpe 2012; McKenna 2002, 2009; McKenna & Gettler 2011; McKenna & Volpe 2007; Volpe, Ball, & McKenna 2013). Apart from their work on infant sleep, I have not encountered a

cultural and critical medical anthropological analysis using critical race theory of an infant sleep project campaign in the U.S. to date. There is, however, a plethora of work by medical and public health professionals and scholars on the topic of racial health inequities, infant mortality, safe infant sleep, and safe infant sleep projects. I am hoping to contribute to the anthropological literature as an anthropologist who does applied and engaged community work within the sub-fields of cultural and medical anthropology with an emphasis on the impact of racism on health.

Organizing the Dissertation

This dissertation is divided into six different chapters. Chapter 1 provides an overview of the context in which this research project took place. Furthermore, it highlights the purpose as well as the contributions of the research. Chapter 2 provides background information on the subject areas of infant mortality, Sudden Infant Death Syndrome (SIDS), and Sudden Unexpected Infant Death (SUID), as well as the racial inequities specific to those areas. Additionally, it provides a historical overview of the national safe infant sleep campaigns – Back to Sleep and Safe to Sleep. Lastly, it includes the contributions to the literature on safe infant sleep from both anthropological and medical points of view. Chapter 3 highlights the two critical theoretical and methodological frameworks used in this dissertation research project – Critical Medical Anthropology and Critical Race Theory. Secondly, Chapter 3 provides an overview of the study design and execution of the research project, highlighting the research methods. This dissertation combined a mixed-methods approach, using both qualitative and quantitative methods, but was primarily qualitative. Additionally, it addresses the limitations of the research. Chapter 4 provides an overview of my research site in the

Mason Square neighborhood area in Springfield, MA. It also gives background information on the organization, Project Baby Springfield (PBS), I worked with from 2009-2014 while conducting my dissertation research. Chapter 4 also covers the development and implementation process of the safe infant sleep educational campaign. Chapter 5 analyzes the data by drawing upon the literature and the theoretical and methodological frameworks highlighted in Chapter 2, in addition to my findings while in the field. Lastly, Chapter 6, Conclusion, summarizes my findings. It also provides a space to explore the limitations as well as the next steps specific to this research.

CHAPTER 2

REVIEW OF LITERATURE

In health and in health care, race matters.

(Randall 2006:19)

Infant Mortality/ SIDS in the U.S.

The concept of infant mortality remains the primary health indicator globally that measures the health of a nation and/or community, and is measured as the number of infant deaths per every 1,000 live births. Internationally, the United States (U.S.) ranks 55th among all countries, and has the highest infant mortality rate among all industrialized nations (CIA World Factbook). Consistently, the top five leading causes of infant death in the U.S. are congenital malformations, prematurity or low birth weight (LBW), Sudden Infant Death Syndrome (SIDS), newborns affected by maternal complications of pregnancy (maternal complications), and accidents (unintentional injuries) (Mathews and MacDorman 2013). Together, these five accounted for 57% of all infant deaths in 2010¹ (Mathews and MacDorman 2013).

Infant mortality is divided into two categories: neonatal mortality and post-neonatal mortality. Neonatal mortality refers to the deaths between birth and the first 28 days of life, whereas post-neonatal mortality refers to the deaths occurring between one month and one year of age. It is important to note that most infant deaths related to both congenital malformations and prematurity or low birth weight (LBW) occur within the

¹ Data used for this dissertation is from 2010 unless otherwise noted, as this is the most comprehensive data year available for national, state, and local data sets that I had access to while writing.

neonatal period, and most infant deaths due to SIDS occur within the post-neonatal period (Mathews and Moore 2013).

Congenital malformations, including deformations and chromosomal abnormalities, are the leading cause nationwide, accounting for 21% of all infant deaths (Mathews and MacDorman 2013). The second leading cause is prematurity, being born less than 37 weeks gestation, and LBW, weighing less than 2,500 grams (5 pounds, 8 ounces), which accounts for 17% of all infant deaths nationwide (Mathews and MacDorman 2013).

The third leading cause of death is SIDS, defined as “the sudden death of an infant younger than 1 year of age that cannot be explained even after a full investigation that includes a complete autopsy, examination of the death scene, and review of the clinical history” (NICHD “What is SIDS?”). SIDS accounts for 8% of all infant deaths nationally, about 2,300 infants annually, an amount that has remained steady since 2001 (Mathews and MacDorman 2013; Moon and Fu 2012). Most SIDS deaths occur in infants between 2 and 3 months of age, and are higher in boy infants than girl infants, although researchers do not know why (CDC, SIDS; Mathews and MacDorman 2013; Mathews and Moore 2013).

SIDS first was created in 1965 under code 795 in the International Classification of Diseases (ICD-8) (Ball and Volpe 2012). From that point on, researchers have been looking to explain these sudden and unexpected infant deaths that cannot be explained. SIDS was, and is, attributed in part to the fact that babies were put to sleep face down, or prone. There are many other documented risk factors, some behavioral (modifiable), and others epidemiological. These include: side sleeping, soft surfaces, loose bedding,

overheating, smoking during pregnancy, environmental tobacco smoke (second or third hand), bed sharing, prematurity and/or low birth weight, young parental age, low parental educational level, inadequate prenatal care, and African-American, American Indian, or Alaska Native heritage (CDC, SIDS; Miller et al. 2011; Moon et al. 2004; Moon and Fu 2012; Trachtenberg et al. 2012).

To this day there is no central conclusion on what causes SIDS. In fact, today SIDS is a diagnosis by exclusion. Scientists have found through autopsies of infants with and without SIDS that infants who died from SIDS may have decreased levels of serotonin in their brain tissue (Matthews and Moore 2013). This would indicate an abnormality of the serotonin receptor binding in the medulla oblongata, a structure in the lower brain stem involved in regulating autonomic function and breathing (Matthews and Moore 2013).

Additional research by McKenna, a biological anthropologist, proposed that SIDS could have something to do with the development of the human respiratory system in infants, especially in the 2-4 month age range when we see higher rates of SIDS deaths (McKenna et al. 2007). This hypothesis was supported by further psychobiological studies, which indicated negative physiological effects on other primates, leading to the conclusion that solitary sleeping infants were deprived of maternal signals and touch, which could be protective for the infant by increasing infant waking and preventing long periods of deep sleep (McKenna et al. 2007). As Ball and Volpe (2012) indicate, there is no SIDS case-control study to date that supports this hypothesis, but there are studies showing that infants who room share (sleeping in the same room with a parent or

caregiver, but in their own sleep space) are at lower risk than sleeping in a separate room alone.

Sudden Unexpected Infant Death (SUID) in the U.S.

As mentioned above, during the post-neonatal period, Sudden Unexpected Infant Death (SUID), which includes SIDS as well as other causes of death including sleep-related deaths, is the leading cause of infant death nationwide among healthy infants 1 month to 1 year old (CDC, SIDS; Matthews and Moore 2013). SUID is defined as “the death of an infant younger than one year of age that occurs suddenly or unexpectedly” (NICHD “What is SIDS?”). After a full death investigation, these deaths are broken down and diagnosed as: suffocation, entrapment, infection, ingestion, metabolic diseases, cardiac arrhythmias, trauma, SIDS, or “undetermined,” when there is no sufficient evidence or information to determine the cause of death (NICHD “What is SIDS?”). Among these, suffocation, overlay, entrapment or wedging, and strangulation are categorized as “sleep-related causes of infant death,” meaning how, where, or with what a baby slept, also sometimes referred to as an “unsafe sleep environment” and/or an “unsafe sleep position” within written reports and death investigations (MA SIDS Center 2014; NICHD “What is SIDS?”).

Nationally, on average there are 4,500 infant deaths categorized as SUID each year, with about 2,300 of these deaths categorized as SIDS (Mathews and MacDorman 2013; Matthews and Moore, 2013; Moon and Fu 2012). Researchers hypothesize that sleep-related deaths in the past were likely diagnosed as SIDS, but today there are more defined categories, as were listed above. It is important to note, however, that SIDS is still a more recognizable and familiar term than SUID or sleep-related causes of infant

death. Thus, the various terms are often used interchangeably, which can be confusing, but it is an important distinction moving forward in the conversation (Moon and Fu 2012).

Back to Sleep Campaign

In the 1970s and 80s, it was standard to place infants in separate rooms for sleep. Additionally, infants were placed prone, on their stomachs, as this reduced sleep-related movement and infants slept more deeply (McKenna et al. 2007). However, given the high number of SIDS deaths that came with sleeping face down, the American Academy of Pediatrics (AAP) implemented a policy change in their Back to Sleep program in 1992. This shift was then followed by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) launch of the Back to Sleep campaign in 1994 to raise public awareness of SIDS. The NICHD campaign emphasized putting babies to sleep on their backs, or supine, and for this reason the name Back to Sleep was used. Since its inception, the campaign is credited with reducing SIDS related deaths by over 50% (Matthews and Moore 2013; NICHD, Explore the Campaign).

Safe to Sleep Campaign

Despite the steady SIDS rates since 2001, other SUID death rates have increased, most notably in the categories tied to sleep-related causes of infant death. Currently, 50% of all SIDS deaths in the U.S. occur when the infant is sharing a sleep surface with someone else (Fu et al. 2010). Research has also shown that infant deaths from accidental suffocation and strangulation in bed (ASSB) has quadrupled in recent years (Moon and Fu 2012; Schnitzer et al. 2012; Shapiro-Mendoza et al. 2009). Bartick and Smith (2014) point out that ASSB includes sleep-related deaths in any location, so the

use of the term “Bed” in ASSB is misleading, given that other sleep surfaces, such as sofas and recliners, have been shown to increase the risk of infant death (Rechtman et al. 2015). They, in fact, suggest using the term sleep-associated suffocation and strangulation (SASS) to ensure clarity in communicating the risks to parents regarding infant sleep environments (Bartick and Smith 2014).

Given the increases in these infant death categories, the NICHD expanded its safe infant sleep campaign during 2012 under a new name, Safe to Sleep. The Safe to Sleep campaign correlated with and incorporated the AAP policy recommendations and guidelines that came out in late 2011 (AAP Taskforce 2011a, 2011b). These guidelines emphasize the following for their level A recommendations, grounded in evidence-based research studies and scientific data:

- 1) *Back to sleep for every sleep*
- 2) *Use a firm sleep surface*
- 3) *Room-sharing without bed sharing is recommended*
- 4) *Keep soft objects and loose bedding out of the crib*
- 5) *Pregnant women should receive regular prenatal care*
- 6) *Avoid smoke exposure during pregnancy and after birth*
- 7) *Avoid alcohol and illicit drug use during pregnancy and after birth*
- 8) *Breastfeeding is recommended*
- 9) *Consider offering a pacifier at nap time and bedtime*
- 10) *Avoid overheating*
- 11) *Do not use home cardiorespiratory monitors as a strategy for reducing the risk of SIDS*
- 12) *Expand the national campaign to reduce the risks of SIDS to include a major focus on the safe sleep environment and ways to reduce the risks of all sleep-related infant deaths, including SIDS, suffocation, and other accidental deaths; pediatricians, family physicians, and other primary care providers should actively participate in this campaign*

(AAP SIDS Taskforce 2011a:1031)

Following these new recommendations by the AAP SIDS Taskforce, the NICHD revised its materials and outreach activities on safe infant sleep seeking out Safe to Sleep Champions nationally to partner in these efforts (NICHD “Key Moments”). Key members of the PBS team have participated in several activities related to this call to action in conjunction with the ongoing safe infant sleep campaign and educational outreach activities in Springfield, which will be highlighted in detail in Chapter 4 of this dissertation. Indeed, it is this area of sleep-related infant death that this dissertation will address through an analysis of the planning and implementation of a safe infant sleep educational campaign by Project Baby Springfield.

Racial Inequities in Infant Mortality/SUID/SIDS/ASSB in the U.S.

As any scholar knows, data can be looked at from a variety of angles. Above I have presented a summary of infant mortality, SUID, and SIDS data for the U.S. population as a whole, but I want to turn to a summary of this data by race and ethnicity. In fact, it is particularly striking to look at the infant mortality data by race and ethnicity. Scholars have demonstrated for other health outcomes that a mother’s educational level, which often correlates with socioeconomic status (SES), corrects for these disparities. However, this is not the case when it comes to infant mortality or birth outcomes in the U.S. (Braveman et al. 2010; Loggins and Drumond Andrade 2013; *When the Bough Breaks* 2008). In fact, a baby born to a non-Hispanic White woman who never graduated high school is more likely to survive infancy than a baby born to a non-Hispanic Black woman with a college degree (Braveman et al. 2010; *When the Bough Breaks* 2008).

Clear health inequities are present, particularly among non-Hispanic Black infants, whose IMRs are consistently more than double the rates of non-Hispanic White infants (Mathews and MacDorman 2013; #Black Lives Matter 2015). The overall 2010 IMR, the number of infant deaths per 1,000 live births, is 6.14 in the U.S., which is a 4% decline from 2009 (Mathews and MacDorman 2013). However, despite the overall decline, when broken down by race and ethnicity,² the difference in IMRs is staggering. The overall IMR for non-Hispanic Black infants in the U.S. is 11.46, which is more than double the overall IMR of 5.18 for non-Hispanic White infants (#Black Lives Matter 2015). In fact, despite the fact that the rate has continued to decline for both groups over time, it is important to note that this gap in IMRs between Black and White infants has been consistently two-fold throughout the past decade (Mathews and MacDorman 2013 ; #Black Lives Matter 2015). Chapter 4 will further address the racial inequities specific to the IMR and other data for both the state of Massachusetts and the city of Springfield.

While research has shown that the overall SIDS rate has declined more than 50% since the Back to Sleep campaign was implemented in 1994, and that the rate has remained steady since 2001, there are still clear racial inequities in the rate of infant deaths between non-Hispanic Black and non-Hispanic White infants (Mathews and Moore 2013; Moon and Fu 2012; NICHD, Explore the Campaign; Schnitzer et al. 2012). Similar to the overall two-fold disparity seen in national infant mortality data rates between non-Hispanic Black and non-Hispanic White infants, when analyzing SUID/SIDS death rates alone, non-Hispanic Black infants also have more than double the

²As of 2000, the US Census counts Hispanic as an ethnic category, yet considers Black and White as racial categories.

rate of death compared to non-Hispanic White infants (Moon et al. 2004; Moon et al. 2010; #Black Lives Matter 2015).

It is important to note that this remains true despite efforts by the NICHD to specifically direct messages on safe infant sleep to African-American families in materials for both parents and grandparents (Moon et al. 2004; Moon et al. 2010). What is also striking is that the racial gap remains across all educational and income categories, and has continued to worsen despite the decline in SIDS rates overall (Moon et al. 2004; Moon et al. 2010; #Black Lives Matter 2015).

According to the National Infant Sleep Position (NISP) study, it is non-Hispanic Black infants who are at the highest risk of death due to SIDS and ASSB (Colson et al. 2013; #Black Lives Matter 2015). While the Back to Sleep campaign has had significant success in decreasing the overall SIDS death rate, other studies have shown that non-Hispanic Black infants are less likely to be placed on their backs to sleep compared to non-Hispanic White and Hispanic infants (Colson et al. 2009; Colson et al. 2013; Hauck et al. 2002). Some studies have also noted that many African-American mothers were fearful of placing their infants on their backs due to fear of choking, this fear rooted in an overall care and concern for the infant's safety and well-being (Colson et al. 2006; Gaydos et al. 2015).

Several studies, including the NISP study, found that there are factors that affect how African-American parents report their infant care practices. One qualitative study found that the Back to Sleep campaign's difficulty in gaining acceptance among African-American parents had to do with the inconsistency in messaging specific to safe infant sleep over time (Colson et al. 2006; Gaydos et al. 2015; Moon et al. 2010). This same

study demonstrated that family member's advice, particularly from older generations, also attributed to the difficulty in effectively reaching African-American parents (Colson et al. 2006; Gaydos et al. 2015; Moon et al. 2010). In fact, these studies have shown a correlation between receiving information about infant sleep and infant care practices and trusting that information from said physician in order for parents to subsequently follow that particular advice (Colson et al. 2006, 2009, 2013; Robida and Moon 2012; Von Kohorn et al. 2010). Additionally, the study by Gaydos and colleagues (2015) found that, if the advice provided by family members contradicted the advice given by a trusted medical provider, the mothers in their study, recognizing that the familial advice may be out of date, were more likely to follow the provider's advice. Additionally, some studies have indicated that direct verbal communication from health providers, over providers just giving handouts with written information, is influential in impacting parental decisions on sleep position and location (Moon and Omron 2002; Robida and Moon 2012). These findings speak strongly to the importance of cultural competency, trust, and effective communication between providers, parents, and caregivers regarding infant care practices throughout all stages of care.

Given the increase in SUID rates due to sleep-related causes and ASSB, it is important to note here that safe infant sleep goes well beyond the message that babies should be put to sleep on their backs. Practitioners and community health advocates frequently use the acronym ABC to communicate the comprehensive message of safe infant sleep with "A" for "alone," which means the baby has his/her own sleep surface that is in the same room with the parents; "B" for "back," consistent with the message since the Back to Sleep campaign began twenty years ago; and "C" for "crib," or bassinet

or pack-n-play, indicating the importance of a separate sleep space that is safety approved, meaning a firm surface, tight fitting sheet, and no blankets, pillows, loose objects, or bumper pads in the sleep space.

These mirror the AAP SIDS Taskforce (2011a, 2011b) recommendations, which advocate for room sharing – meaning that infants sleep in the same room with their parent(s) or caregiver(s) –versus bed sharing –when an infant sleeps on the same sleep surface as another person (Moon and Fu 2012). The reality is that many parents and caregivers in the U.S. bed share with their infants. In fact, the NISP study found that 45% of all parents’ bed shared with their infants at least some of the time (Colson et al. 2013). A recent meta-analysis paper found an increased risk of infant death for infants who bed shared, but could not discern between those who bed shared in a parental bed compared to other sleep surfaces, such as a couch (Venneman et al. 2012).

Bed Sharing

Data has shown that more than half of all the SUIDs in the U.S. happen when an infant is sharing a sleep surface with another person, usually a parent (Moon et al. 2010). In fact, several research studies have shown an increased risk of SUID when infants bed share, and especially so when in the presence of parental smoking (CDC “SUID”; Miller et al. 2011; Moon et al. 2004; Moon et al. 2010; Vennemann et al. 2012). Additional bed sharing risk factors include alcohol consumption, medications, young infant age (under 3 months), use of bedding and soft surfaces for sleep, bed sharing with persons other than parents, and bed sharing all night long (Mathews et al. 2015). Bartick and Smith (2014) point out that the emphasis on the danger of bed sharing has unintended consequences for sleep-related infant death. For example, for feeding their baby or getting their baby to

sleep, parents may be more likely to move to the couch or recliner. These practices which are included among the additional risk factors noted above because the chosen locations provide what are considered “soft” surfaces for sleep (Bartick and Smith 2014; Mathews et al. 2015; Rechtman et al. 2014).

Bed sharing, also sometimes referred to as co-sleeping or co-bedding, is a highly contentious issue. It is often divisive both between and within disciplines, most notably among social scientists, public health, and medical professionals, as well as among parents and grandparents, due to multiple interpretations and experiences in addition to personal and cultural values and beliefs (Ball and Volpe 2012; Fu et al. 2010; Vennemann et al. 2012; Volpe et al. 2013).

The central issues framing this divide on bed sharing center on who is bed sharing, where and how bed sharing is taking place, and what way bed sharing is being done (Ball 2009). The greatest divide seems to be between three factions: pediatric medicine, physical/biological anthropologists, and the breastfeeding community. The anthropologists argue that an anthropological approach would be helpful, and yet is missing from contemporary pediatric sleep research (Gettler and McKenna 2011). Anthropologists have been writing about bed sharing (co-sleeping) and unexplained infant deaths for more than two decades; they have drawn upon an evolutionary perspective based on cross-species, cross-cultural, historical, and physiological evidence exploring the Western ideas that infants should sleep alone and should be undisturbed (Gettler and McKenna 2011; McKenna et al. 2007). Pediatric medicine practitioners have also been writing extensively about infant sleep, and tend to draw upon case-control epidemiological studies. Increasingly, many of the studies by pediatric medicine

practitioners have included more qualitative studies, and/or a mixture of both qualitative and quantitative methods; these are drawn upon in the subsequent section below on bed sharing and non-Hispanic Black families.

Interestingly, the AAP initially recommended against bed sharing back in 1990 only when certain risk factors were present (AAP Taskforce 2000). As more data became available throughout the first half of the 2000s, the AAP taskforce issued a policy statement in 2005 in which they recommended against bed sharing entirely (AAP SIDS Taskforce 2005). The physical/biological anthropologists who write about infant sleep and bed sharing have expressed their disappointment with this position calling it “highly problematic given the intertwined physiology of the sleeping human mother-infant dyad” (McKenna et al. 2007:135). The 2005 AAP recommendation against bed sharing was carried over into the AAP’s 2011 policy recommendations. The new recommendations, however, emphasize room sharing, that is, an infant in the same sleep location with the parent(s), but on his/her own sleep surface (AAP SIDS Taskforce 2011a). Room sharing is seen as a protective factor against SIDS (Ball 2009). This new recommendation for room sharing seems to be a mutually overlapping position for all sides. This is still contested by the physical/biological anthropologists and breastfeeding community for the exclusion of sharing a sleep surface, which they see as a deterrent to breastfeeding and mother-infant bonding (Ball 2009). However, the 2011 AAP policy recommendations explicitly encourage and recommend breastfeeding (AAA SIDS Taskforce 2011a).

Bed Sharing and non-Hispanic Black Families

Strikingly, among all of the anthropological literature I have encountered to date on the bed sharing debate, not one of the studies addresses the racial disparities specific to non-Hispanic Black families in the U.S., despite the glaring inequity in infant deaths for Black infants across the board (#Black Lives Matter 2015). The anthropological literature addresses various studies in the U.S. among mothers and infants, but there is no acknowledgement of race or racism. The literature does address studies from a range of cross cultural contexts internationally, but all are in Western contexts (United Kingdom and New Zealand).

The NISP study found that non-Hispanic Black infants are most likely to share a sleeping space with another individual (Colson et al. 2013). In fact, non-Hispanic Black infants are 3.5 times more likely to share a bed, and are more likely to do so than any other racial or ethnic group in the NISP Study (Colson et al. 2013; Moon et al. 2010). Bed sharing continues to increase for non-Hispanic Black infants, while this is not the case among non-Hispanic White infants (Colson et al. 2013). Fu and colleagues (2010) found a two-fold increased risk of SIDS for non-Hispanic Black infants who bed shared, when compared with all other forms of sleeping combined (#Black Lives Matter 2015). Furthermore, their study found an increased risk of death when bed sharing was combined with other factors present: pillows, soft sleep surfaces, non-use of pacifier, smoking, and younger infant age (Fu et al. 2010).

A number of qualitative research studies in recent years have discussed the various reasons why many non-Hispanic Black parents bed share (Chianese et al. 2009; Colson et al. 2013; Herman et al. 2015; Joyner et al. 2010; Mathews et al. 2015). All of

these studies demonstrate that the primary reasons why parents bed share center on the themes of infant safety and comfort combined with a desire to be in close proximity to the infant (Colson et al. 2013; Fu et al. 2010; Herman et al. 2015; Joyner et al. 2010; Mathews et al. 2015). Among low-socioeconomic status families, many parents discussed additional factors, including a lack of adequate space and financial constraints, as impacting decisions to bed share (Fu et al. 2008; Joyner et al. 2010). Chianese and colleagues (2009) also found other reasons – such as better sleep, family tradition, and a child’s illness – to be factors that influenced parents’ decisions to bed share.

Other studies have shown bed sharing to be more common among families who breastfeed, but these studies were not specific to African-American families (Ateah and Hamelin 2008; McKenna et al. 2007). It is important to note that this correlation between bed sharing and breastfeeding is not well established in the literature as it pertains to African-American families (Fu et al. 2008). Joyner and colleagues (2010) found in their study that breastfeeding did not impact African-American mothers’ decision to bed share regardless of socio-economic status. Their study did find that bed sharing facilitated both breastfeeding and formula feeding among these mothers (Joyner et al. 2010). However, another study found that breastfeeding did impact African-American mothers’ decision to bed share, but only among those with low socio-economic status (Kadokia et al. 2015). More important than sleep arrangement, however, they found that the commitment to breastfeeding can be diminished if mothers are skeptical that breast milk is actually better than formula (Kadokia et al. 2015). This is corroborated by another study that highlighted that African-American mothers are twice as likely to believe in the benefits of formula as compared to breast milk (Nommsen-Rivers et al. 2010).

Bedding and Non-Hispanic Black Families

In addition to looking at infant sleep position and infant sleep location, the NISP study also looked at bedding use and found that non-Hispanic Black as well as Hispanic infants were more likely to have bedding (blankets, comforters, quilts, pillows, soft objects, etc.) than non-Hispanic White infants (Shapiro-Mendoza et al. 2015). These items are considered hazardous when placed under the infant or loose in the infant sleep environment, increasing SIDS risk 5-fold, and up to 21-fold when the infant is placed face down (prone) (Hauck et al. 2003). Researchers are confounded by the fact that Hispanic infants do not have SIDS and sleep-related death rates similar to non-Hispanic Black infants, but rather mirror the non-Hispanic White rates (Shapiro-Mendoza et al. 2015). Some studies have suggested that the rates may be higher among non-Hispanic Black infants whose mothers have lower rates of breastfeeding (a protective factor against SIDS), higher rates of smoking, and higher preterm birth and LBW rates, all of which are considered risk factors for SIDS (AAP 2011a; AAP 2012; Mathews et al. 2015; Shapiro-Mendoza et al. 2015).

Ajao and colleagues (2011), in their study among African-American families, found that, regardless of socio-economic status and level of education, the parents in their study indicated that they used soft bedding and/or soft objects primarily for the purposes of infant comfort and safety, and secondarily for aesthetics. This study demonstrated that many parents had the perception that soft bedding and bumper pads in a crib would help keep their infant safe, when in reality there is an increased risk of SIDS, accidental suffocation, entrapment, or strangulation from these items when placed in a crib with an infant (Ajao et al. 2011; Hauck et al. 2003; Kemp et al. 2000; Thach et al. 2007).

CHAPTER 3

THEORY AND METHOD

Critical theory insists that thought must respond to the new problems and the new possibilities for liberation that arise from changing historical circumstances. Interdisciplinary and uniquely experimental in character, deeply skeptical of tradition and all absolute claims, critical theory was always concerned not merely with how things were but how they might be and should be.

(Bronner 2011:1-2)

Critical Theories

This dissertation draws upon two critical theories, Critical Medical Anthropology and Critical Race Theory. These theoretical and methodological frameworks are employed in order to emphasize the existence and role of power and its impact on health outcomes by race. This is essential in order to frame and analyze the Black health inequities specific to infant mortality, and more specifically to sleep-related infant death among African-American infants, as highlighted throughout this doctoral dissertation research project within the Mason Square neighborhood of Springfield, Massachusetts .

Critical Medical Anthropology

As anthropology continued to develop as a discipline, an additional subfield, medical anthropology, emerged in the 1940s after World War II. Medical anthropology bridges two of the four main subfields within the discipline: cultural and biological, and has become one of the largest areas of interest beyond the traditional subfields (Singer 2012). Critical medical anthropology (CMA) is a specific theoretical framework that emerged in the late 1980s. Indeed, it grew out of a need to address the limitations within the discipline of medical anthropology from the perspective of the political economy of

health. This discipline was lacking in its analysis of health-related beliefs and behaviors at the local level. Both required a further analysis or questioning of the larger causes and impacts on individual decision making and behaviors specific to health-related issues (De los Angeles Núñez Carrasco 2008; Singer 1989; Singer and Baer 2012). Singer and Baer (2012) highlight that “CMA emphasizes structures of power and inequality in health care systems and the contributions of health ideas and practices to reinforcing inequalities in the wider society” (39). Furthermore, CMA allows for a discussion of individual agency and experience, while simultaneously addressing the socially constructed structures that exist within the institutions and the larger society (De los Angeles Núñez Carrasco 2008; Singer and Baer 2012).

Additionally, Anglin (1997) highlights the importance of applied work within a CMA approach when she states, “In the context of health care in the United States, medical anthropology has the opportunity to draw upon the experiences of people at the margins to better articulate the kinds of changes needed to strengthen existing approaches, and to propose alternatives” (1368). Her call for praxis mirrors Singer’s (1995) assertion that CMA “[...] cannot achieve its goals without serious consideration of the appropriate application of critical knowledge to the practical domain of health [...]” (98). This is to say, those of us who identify and practice as critical medical anthropologists are required to not just theorize and to simply be in the field, but to also do the real work – on the ground and in the trenches – to challenge existing power structures that impact people’s lives and health (Singer 1995). Singer (1995) refers to CMA as “consciously political” (81). He further asserts that CMA “[...] is peculiarly anthropological in the sense that it is holistic, historical, and immediately concerned with

on-the-ground features of social life, social relationships, and social knowledge, as well as with culturally constituted systems of meaning” (Singer 1995:81). Indeed, CMA is not only a theoretical approach, but also a tool of analysis for ethnographers and practitioners to develop and subsequently draw upon a critical cultural lens in order to address and analyze the social and structural inequalities such as poverty, discrimination, and violence and how these impact people’s health and well-being (De los Angeles Núñez Carrasco 2008; Farmer 2005; Randall 2006; Singer 1995; Singer & Baer 2012).

An in-depth understanding of these structural inequalities and historical conditions is critical in the analysis of the data compiled for this dissertation research project on a safe infant sleep project. However, while implicit in the above description, I assert that racism should also be included explicitly in the list of structural inequalities(#Black Lives Matter 2015). Racism is, and has always been, about power. Given its documented historical and contemporary role in the social, political, economic lives of Black Americans for nearly 400 years, and in their psychological, and physical well-being, racism is also an essential component in the analysis of the data compiled for this study (Boone 1989; Bridges 2011; Hoberman 2012; Lane 2008; Randall 2006; Skloot 2010; Washington 2006). Thus, in addition to CMA, I include a second critical theoretical and methodological perspective in my analysis that explicitly addresses the role of race, racism, and power – Critical Race Theory.

Critical Race Theory

Critical Race Theory (CRT) is defined as a movement comprised of “activists and scholars interested in studying the relationship among race, racism, and power” (Delgado and Stefancic 2001:2). Some of the key individuals who have influenced CRT include European philosophers Antonio Gramsci and Jacques Derrida. Additionally, it draws from ideas put forth from “the American radical tradition” (Delgado and Stefancic 2001:4) including Sojourner Truth, Frederick Douglass, W.E.B. DuBois, Cesar Chavez, and Martin Luther King, Jr., as well as the Black Power and Chicano movements in the 1960s and 1970s in the United States (Delgado and Stefancic 2001). CRT demonstrated a growing awareness that new forms of racism, as well as other forms of oppression with which it intersects, persisted despite the accomplishments of the civil rights movement. CRT grew during the mid-1970s out of the fields of critical legal studies and radical feminism which arose throughout the previous decade, and then spread to other academic disciplines, appealing to many given its activist component (Brayboy 2005; Delgado and Stefancic 2001; Ford and Airhihenbuwa 2010a, 2010b).

CRT is rooted in four primary principles, which provide the basis of its application in the real world. The first tenet asserts that “racism is ordinary,” which is to say “the usual way society does business, the common, everyday experience of most people of color in this country” (Delgado and Stefancic 2001:7). The second adds a further dimension to racism’s ordinariness, what Delgado and Stefancic (2001) call “material determinism” (7), which focuses on the ways in which racism serves to benefit the dominant group (Whites), while it simultaneously serves to disadvantage people of color. Within a society where racism is ordinary, Whites are automatically given

privilege, White privilege, and as such, there is no incentive (except I would argue a moral incentive if you believe and are committed to achieving equity) to address and dismantle racism.

A third feature of CRT “holds that race and races are products of social thought and relations” (Delgado and Stefancic 2001:7). This is what anthropologists and other social scientists refer to as the social construction of race perspective, which asserts that “races” are “not objective, inherent, or fixed, they correspond to no biological or genetic reality; rather, races are categories that society invents, manipulates, or retires when convenient” (Delgado and Stefancic 2001:7).

Despite “race” not having a biological or genetic basis, “race” remains very real in the reality of the experiences and material outcomes among people of color in the United States, and especially so for African-Americans, although certainly not exclusively (Boone 1989; Bridges 2011; Hoberman 2012; Lane 2008; Randall 2006; Skloot 2010; Washington 2006). This principle is further highlighted by the fourth tenet, which looks at the process of racializing different groups and the consequences of this process of “differential racialization” (Delgado and Stefancic 2001:8). It is important to note that this is a process that changes over time, but is always based on the needs of those in the dominant group, those who most benefit from a racialized system even if individually nothing is done.

Within the public health field CRT is a relatively new arrival, first used in the discipline’s main journal in 2010 by scholars Ford and Airhihenbuwa (2010b) who developed the concept of Public Health Critical Race praxis (PHCR). Ford and Airhihenbuwa (2010b) argue that PHCR is a way of “facilitating the use of CRT for

health equity research” (1390). They state that “although race remains salient to public health in a variety of ways, the field’s theoretical and methodological conventions inadequately address the complexity with which structural racism influences both health and the production of knowledge about populations, health, and health disparities” (Ford and Airhihenbuwa 2010a:S30). Thus, CRT and PHCR are similar in that they both “attempt to move beyond merely documenting health inequities toward understanding and challenging the power hierarchies that undergird them” (Ford & Airhihenbuwa 2010b:1390).

Given that CRT focuses on key areas of racial subordination, prejudice, racism, and inequity, it remains a necessary and essential tool for analysis as “it not only tries to understand our social situation, but to change it; it sets out not only to ascertain how society organizes itself along racial lines and hierarchies, but to transform it for the better” (Delgado & Stefancic 2001:3; Graham et al. 2011). Drawing upon Ford and Airhihenbuwa’s (2010b) application of CRT within public health research on health equity allows me to similarly draw upon CRT in conjunction with the theoretical and methodological framework of CMA within this dissertation research study, as I explain and analyze the processes undertaken by Project Baby Springfield in the development and implementation of its safe infant sleep educational campaign.

Objectives of Research

The overall objective of this research study is to use grounded theory and a primarily qualitative methods approach in order to describe and analyze the various factors impacting the development, implementation, and sustainability of a safe infant sleep educational campaign in the context of structural violence and poor health

outcomes within Springfield, MA. As explained above, this project draws upon the theoretical and methodological frameworks of critical medical anthropology and critical race theory. Furthermore, it is my goal to have this research summary compiled and shared with my team members at PBS to draw upon future educational and social justice related efforts within the City of Springfield regarding health equity.

Study Design

I utilized a primarily qualitative methodology in this dissertation research study, but am also drawing upon quantitative data gathered through PBS-designed surveys as well as state data available from the Massachusetts Department of Public Health (MADPH), with 2010 being the most recent year of data available consistently for national, state, and local sources while writing this dissertation. The 2011-2012 data for the state of Massachusetts was released while writing, so I will address this in Chapter 5, in conjunction with Project Baby's future efforts and goals. The data gathered via meeting notes, field notes, and numerous internal documents during my six-year tenure with PBS will also be drawn upon for this dissertation project.

My qualitative methods rely upon participant observation, given my role as a PBS team member for six years and project coordinator during 2013 when PBS implemented its safe infant sleep educational campaign program and outreach efforts in Springfield. I also draw upon both semi-structured and informal interviews with PBS team members, PBS partners, and representatives of the community. With the recruitment help of 2 key representatives within the faith-based community, I was also able to conduct 2 focus groups during the summer of 2012 prior to the development of the safe infant sleep campaign primarily among African-American women and men, one among mothers and

the other among grandparents, in order to facilitate a conversation about how parents and caregivers put their babies and grandbabies to sleep, where they sleep, and why, in order to illuminate people's individual stories and experiences.

PBS also had 2 summer interns from Amherst College during the summer of 2012. They also conducted preliminary focus group sessions with young mothers, which they had access to through other PBS team members connections. I draw upon their initial findings as secondary research in order to help explain the PBS team's extensive process in developing the safe infant sleep campaign implemented in 2013. Additionally, along with 3 other PBS team members, I did a material analysis, both visual and textual, of a variety of safe infant sleep brochures, posters, and campaigns from around the U.S. in preparation for the development of the campaign in Springfield.

I was also a part of the PBS team during the four-year planning process that culminated in the Maternal Infant Strategic Plan Summit held in June 2012. PBS and its partners created an Action Plan and Implementation Framework in order to address the various factors impacting the poor birth outcome inequities in Springfield. The following six goals outlined below were developed with the goal of moving toward a comprehensive system that would reduce the racial inequities in birth outcomes throughout the city:

- 1) To improve the quality of prenatal and postnatal care*
- 2) To provide care between conception for women with prior adverse pregnancy outcomes*
- 3) To improve access to preconception care in an integrated, caring system*

- 4) *To strengthen the involvement of fathers*
- 5) *To support working mothers and fathers*
- 6) *To un-do racism*

(Lewis 2011)

Following the Summit, based on potential funding as well as the need for a tangential starting point to comprehensively address the high IMR in Springfield while also addressing the six areas from the Strategic Plan, PBS decided to focus its initial efforts on developing a culturally and linguistically relevant public education campaign aimed at providers as well as mothers, fathers, and extended families, in addition to the larger community. The goal was to address the topic of safe infant sleep.

This was an essential and necessary effort, given that between 2006 and 2011 (most recent data available at that time) in Springfield, there were a total of 34 sudden unexpected infant deaths (SUIDs), defined as “the death of an infant younger than one year of age that occurs suddenly or unexpectedly” (NICHD “What is SIDS?”). Twenty of the 34 deaths (nearly 60%) were associated with an “unsafe sleep environment” or an “unsafe sleep position,” with the majority of these deaths among African-American and Latino/a babies (MA SIDS Center 2014).

Researcher Positionality

As a result of several of my own racial and health experiences, I made the conscious choice to seek out a dissertation project that would involve community-based work, be collaborative, and action-oriented, with an already-identified need within that community. The goal was to combine my interests in health and social justice from an anthropological lens with a community-based and –identified health issue. I answered Dr. Balder’s call for volunteers during our initial encounter following his presentation on

infant mortality in Springfield, and have been a part of the Project Baby Springfield team for the past 6 years, serving as the Project Coordinator during 2013 while conducting my dissertation research.

This is not the dissertation I thought I would be writing when I entered into my doctoral studies. Indeed, what I planned to pursue versus what I ended up doing is metaphorical in that the shift signifies the inevitable ebb and flow that almost always occurs for those of us who engage in the qualitative research process.

About 3 years into my doctoral studies, I began struggling with the design of my proposed dissertation research project. I was going to focus specifically on issues of race and beauty among multiple generations of Dominican women living in Lawrence, MA, a city with a significant Dominican population as well as a long history of flows among different immigrant groups. From an ontological standpoint, I found my proposed project interesting and exciting. I planned to build upon my preliminary research done as part of my Master's thesis, which had focused on the differing aspects of racial and ethnic identity among Dominican women living in the greater Boston area. Epistemologically speaking, however, I had come to a crossroads in those early years of my doctoral work. I had invested a significant amount of time and energy into the planning and development of the research, but I was also working several jobs in order to survive, and given the 2.5 hour distance between Amherst and Lawrence, I did not have the time, connections, or financial resources to start to lay the foundation for my project.

I felt frustrated by this, and also felt like something was missing in terms of my research, but I could not quite put identify it. During the fall of 2008, however, I finally put my finger, literally and figuratively, on that "thing" that would lead me to my

dissertation project with PBS. During a self-breast examination, my finger landed upon a lump in my right breast. Indeed, this was not quite the answer I was looking for, but finding the lump and all that followed in that six month period impacted me in such a way that I re-evaluated and subsequently changed the design, focus, and direction of my dissertation research.

I continue to reflect upon the fact that I walked away from those experiences within the U.S. health care system feeling marginalized and silenced, while simultaneously aware of the multiplicity of privileges I embody as a White, heterosexual, female with health insurance who can ostensibly “pass” for middle class, despite my current status as a graduate student. I also began to think deeply about all of those who had come before me within the system itself. I started to wonder about other women’s experiences at the hands of the health care system in general, and I started to ask how I might go about giving voice to my experience as well as their experiences through my future research. I had so many questions. I could not help but wonder what the experiences were for women of color, for poor and working-class women, for women who are uninsured or under-insured, for women who do not have the flexibility of a college teaching schedule to repeatedly take significant time off of work, for women who do not have paid time off from work, for women who have to rely on public transportation, for the women for whom English is not their first language, for women who do not feel comfortable speaking up and asking questions, and lastly, for those women for whom it is culturally inappropriate to question authority figures? These questions led to more questions, and I realized that there were no answers, just more questions.

Indeed, I realized that I had arrived at a professional crossroads as a result of this personal experience. I had always made the conscious choice to position myself, my pedagogy, and my planned research within an intersectional approach because it is a perspective from which I have been able to understand and situate my early experiences, especially those that were simultaneously raced, classed, and gendered. Furthermore, an intersectional approach has given me a perspective that allows for an understanding of racism as linked, rooted, and embedded within the very fabric of our nation's history, its institutional structures, and its overarching patriarchal, heterosexist, capitalist, and racial ideologies. Collins (2000) supports this notion, when she states that, "within U.S. culture, racist and sexist ideologies permeate the social structure to such a degree that they become hegemonic, namely, seen as natural, normal, and inevitable" (5). In my teaching, I have always drawn upon the fundamental principles and philosophies of respect, collaboration, and reciprocity, **and** feel strongly that these were important aspects to the research process as well. In fact, the time had arrived where I had the choice to move from theory to praxis (McClaurin 2001) within my dissertation research.

Limitations of Study

This study is subjective, based on the lens through which I have experienced and interpreted the information I gathered and that which the research participants shared with me. I am trained as a cultural anthropologist, which has informed and shaped my theoretical and methodological approaches. One limitation I see is that I am not a Springfield resident, nor am I from Springfield, two very important aspects that hold significance among residents in this small urban city where families have often lived for

generations, and thus, emphasized my outsider status in the field despite the number of years engaged in the project.

Additionally, my whiteness and status as a graduate student researcher also contribute to my outsider status. Although I would add that my whiteness is a questionable variable, as I am not always read as White in communities of color. In fact, I am frequently read as mixed in some way. This happened when I first attended the Springfield Health Disparities Project meeting I wrote about in chapter 1 of this dissertation. After the meeting, my colleague, who is a light-skinned Puerto Rican woman, but often read as White, and I were talking with Betty Agin, the African-American woman who welcomed us to her project and meeting that day. She turned to my colleague and said, “Why would a White girl like you want to come work in Springfield”? What was particularly interesting was that she did not say that to both of us. The fact that Betty passed me was not new to me, as this has happened multiple times in a variety of contexts and situations over the past 20 years in my interactions within Black, Latino, and mixed race communities and individuals.

Lastly, some of the factors that helped me gain access and build rapport and trust with several community members and organizations throughout the dissertation process were: my bilingual Spanish skills, my consistent work for six years on the PBS team, my demonstrated commitment to social justice issues, and perhaps most importantly, my continued presence at community events and health fairs throughout the city gave me a platform from which I was visible and active within the community and the Mason Square neighborhood in particular.

CHAPTER 4

DATA

Research Site – Springfield, MA

Springfield (pop. 153,060) is the third largest city in Massachusetts (MA), and is located in Hampden County in the western region of the state (Massachusetts Department of Public Health (MADPH) 2013; U.S. Census Bureau 2013). It is the largest city in Hampden County, which has the lowest county health rankings of all of MA (14th out of 14 counties). Springfield residents having lower levels of education, income, and employment when compared to the rest of the state (County Health Rankings 2014).

According to the most recent U.S. Census data (2010), the population of Springfield is 38.8% Hispanic (approximately 33% Puerto Rican), 36.7% non-Hispanic White, 22.3% Black, and 2.3% other races (U.S. Census Bureau 2013). The per capita income for employed individuals in the city is \$18,400, just over half the per capita income for MA (\$35,000), and significantly less than the national per capita income level (\$28,000). Twenty-seven percent of individuals in Springfield live below the poverty level, nearly double the state (10.7%) and national rates (14%) (U.S. Census Bureau 2013).

Education level is shown to be directly correlated to income, and this is starkly evident in Springfield. Seventy-six percent of residents have received a high school diploma (versus 89% for MA and 85% for the U.S.), but only 17% of Springfield residents hold a bachelor's degree or higher (versus 39% for MA and 28% for the U.S.). It is important to note that Springfield is located within thirty miles of over thirty universities and colleges, yet access to these institutions remains limited, highlighting just

one of the challenges faced by many city residents in addition to other social and structural barriers (U.S. Census Bureau 2013).

Springfield is composed of seventeen distinct neighborhoods, each with unique ethnic, cultural, and socio-economic backgrounds, varied health care access, in addition to other characteristics. Close analysis has identified markedly different IMRs across the seventeen neighborhoods, and has started to correlate these with other measurable neighborhood attributes. The communities of Old Hill, Upper Hill, Bay, and McKnight, together referred to as Mason Square, which are predominantly African-American neighborhoods although increasingly Latino as well, have persistently low rates of prenatal care, low birth weight (LBW) and higher IMRs (Lewis 2011; MADPH 2013).

IMR/SUID/SIDS in Springfield

Although the state of MA has the fourth lowest IMR in the country, Springfield has been faced with IMRs that drastically exceed both the national rates and the Healthy People 2020 goals for Maternal, Infant, and Child Health (Mathews and MacDorman 2013). While the statewide IMR of 4.4 is notably lower to the national rate of 6.14, the IMR for Springfield (9.2) is more than double the state rate (4.4) (MADPH 2013; Mathews and MacDorman 2013). In fact, for 2010, Springfield has the second highest IMR among the 30 largest communities in the state, and the highest IMR (8.8) among the 30 largest communities in MA for the 2008-2010 three-year average (MADPH 2013).

The impact of racial and ethnic disparities highlight a dire need to address the inequities facing African-American mothers in the Springfield community, whose IMR in 2010 was 12.63, more than double the rate for non-Hispanic, White mothers in Springfield at 5.86 (#BlackLivesMatter N.d.). Both the non-Hispanic, Black and non-

Hispanic, White IMRs for Springfield are slightly higher than the national rate of 11.46 and 5.18, respectively (MADPH 2013, Mathews and MacDorman 2013).

While the greatest disparity in Springfield is seen between non-Hispanic, Black and non-Hispanic, White infant mortality, with the more than two-fold gap, there is also a significant disparity in the IMR among Hispanic mothers in Springfield, whose IMR was 8.33 (MADPH 2013). It is important to highlight that nationally Puerto Ricans have a much higher IMR (7.10) than other Hispanic ethnic groups combined, with the overall national IMR of 5.25 for Hispanics (Mathews & MacDonald 2013). Given that the largest Hispanic ethnic group in Springfield is of Puerto Rican descent, PBS has inferred that this disparity in the IMR is reflective of the larger gap seen nationally, despite the fact that the state of MA does not break down IMRs by ethnicity within the Hispanic population because the numbers are too small to be statistically relevant.

Among the 30 largest communities in MA for 2010, Springfield has the second highest LBW percentage, 9.8% as compared to the state average of 7.8%. There is a clear racial and ethnic disparity here as well, with the highest percentages among non-Hispanic, Blacks (10.74%) and Hispanics (10.3%) compared to 8.01% for non-Hispanic, Whites. Additionally, prematurity percentages show similar differences between the city and state averages, with an average of 11.5% for Springfield as compared to the state average of 8.6%. Non-Hispanic, Blacks (10.13%) and non-Hispanic, Whites (10.55%) have similar outcomes, with the highest percentages of prematurity being among Hispanics (12.41%) (MADPH 2013).

Other contributing factors to the high IMR in Springfield include adequate prenatal care (APC), rates of teen pregnancy, rates of smoking during pregnancy, and

breastfeeding. Prenatal care is critical for pregnant mothers, not only to ensure a healthy pregnancy, but also to identify developing problems as well as provide appropriate education and interventions. In 2010, 75.6% of mothers in Springfield received prenatal care in the first trimester compared to 83.93% of mothers in the state, yet only 71.8% of mothers in Springfield received APC compared to 84.9% of mothers statewide. APC is defined as prenatal care begun by the 4th month of pregnancy with at least 80% of the recommended visits received by the time the mother gives birth (MADPH 2013; March of Dimes, Peristats). Based on the 2010 state data set, Springfield again has the second lowest rate (71.8%) among the 30 largest communities in the state for the percentage of mothers receiving APC, and this becomes even more evident when the racial/ethnic disparities are taken into account. Only 68.51% of non-Hispanic, Black mothers and 68.6% of Hispanic mothers had APC compared to 81.91% of non-Hispanic, White women (MADPH 2013).

In Springfield, 19.31% of mothers received inadequate or no prenatal care compared to the state rate of 8.5%. This rate is even higher among non-Hispanic, Black mothers (23.2%) and Hispanic mothers (21.71%) in Springfield compared to 10.34% of non-Hispanic, White mothers, indicating more than a two-fold difference (MADPH 2013). Springfield also has the 3rd highest rate (54.3%) of teen pregnancy in MA. Although rates of teen pregnancy rates have declined by more than 30% between the years 2000-2010 in Springfield, the city's rates are still nearly three-fold the state rate of 17.1% (MADPH 2013).

Another factor contributing to higher IMRs has to do with high rates of smoking during pregnancy, a high risk factor contributing to LBW. Smoking after birth is also a

risk factor for SUID/SIDS. This is yet another issue that needs to be addressed across all racial and ethnic groups in Springfield, as once again the city ranks fifth on the list of cities with the highest percentage of smoking during pregnancy among the 30 largest communities in MA with a rate of 12.8% (MADPH 2013).

Lastly, according to the American Academy of Pediatrics (AAP), breastfeeding is linked to improved health outcomes, as well as having a protective effect against SIDS (AAP 2011a, 2011b). Despite a 5.8% increase since 2006, Springfield still has the 3rd lowest percentage (67.9%) of mothers who breastfeed at discharge from the hospital after birth, or with plans to breastfeed, among the 30 largest communities as compared to the state rate of 82.9% (MADPH 2013).

While PBS's efforts span the whole city, our educational and outreach efforts have been concentrated more specifically in the Mason Square neighborhood, which has had persistently low rates of prenatal care, LBW, and higher IMRs (Lewis 2011, MADPH 2013). In addition to the racial inequities present in this neighborhood, many of PBS's contacts and partners are located within Mason Square. This allows for less of an outside presence within the neighborhood and events. Additionally, PBS pushpin-mapped all infant deaths in the city of Springfield from 2006-2009 and 2009-2011, and was able to identify significant clustering within a few particular areas and zip codes in the city. One of the areas with a higher number of pushpins is the Mason Square neighborhood. Thus, given the connections and contacts already established, along with the data indicating that Mason Square was an area of concern regarding high IMRs, Mason Square became the focus for continuing our outreach efforts in the neighborhood at different events and through different community partners.

History of Project Baby Springfield

Project Baby Springfield (PBS), formerly known as the Springfield Fetal & Infant Mortality Review (FIMR) Taskforce, changed its name to PBS in 2012, as it had long moved on from an infant death review process to doing educational outreach activities within the larger Springfield community. PBS functions as a subgroup of the Maternal Child Health (MCH) Commission, which falls under the City of Springfield's Department of Health and Human Services (SDHHS), and has played an active role in the Springfield community since 1991. Since its inception, PBS has focused its efforts towards identifying risk factors present during a woman's lifespan instead of solely during pregnancy and the postpartum period.

Together with various community partners, PBS represents a diverse group of cross-sector stakeholders coming together to address birth outcome inequities in Springfield, MA. It is a volunteer-based working group that meets monthly. PBS is headed up by Dr. Andrew Balder, a local physician at the Baystate Mason Square Neighborhood Health Center. PBS is made up of professionals from a variety of fields – doctors, nurses, mental health providers, public health professionals, community health workers, administrators, representatives from state and local government, as well as academics, who are primarily involved in teaching, not research. There are individuals who are on the team both live and work in the city in the related health fields or other community organization, but there were no community members outside of the health realm, nor were there youth who were members of the team. Thus, this group represents a select group of individuals and perspectives, which, while important, do not necessarily

encompass those of everyone in the neighborhood community given their social, political, and/or economic status and power.

Just before I joined the taskforce in early 2009, the then FIMR team compiled a report based on a series of focus groups funded through the Massachusetts Department of Public Health (MADPH). These were conducted with African-American mothers in Springfield between 2007 and 2008, and they identified a number of barriers to receiving prenatal care, namely, lack of child care, lack of health information, lack of transportation, and inflexible appointment scheduling. A notable key finding of the report was the identification of provider racism and impersonal treatment as primary reasons that women did not adhere to their prenatal appointment schedule (Springfield FIMR 2008).

In April of 2009, I saw a presentation of this initial focus group data and data on the high infant mortality rate for Springfield given by Dr. Balder and two other PBS team members at a monthly Saturday morning meeting with the Springfield Health Disparities Project (now Universal Community Voices Eliminating Disparities – UCVED). After this presentation, I was compelled to join their efforts. I was looking for a dissertation project that would be community-based and allow me to combine my interests in health and social justice. At the end of their presentation, they stated that they were looking for others to join their group in working to address the racial inequities highlighted in their presentation, so I approached them and explained my interest as well as the need for a dissertation project, and they invited me to join their team.

Review of Safe Infant Sleep Campaigns from across the US

Prior to securing funding for PBS's Safe Infant Sleep Campaign, in January 2012, a small subset of the PBS team met to review other safe infant sleep campaigns from across the country. The smaller working group consisted of 4 PBS team members including myself, Dr. Balder, and two nurses – one a maternity nurse from one of the hospitals in Springfield, and the other a public health nurse employed by the city. We reviewed the safe sleep messaging materials given out for free by the federal government through the NICHD in addition to those from varying SIDS and/or safe sleep organizations as well as those from varying states and counties from across the country. Many of these entities shared their programming and outreach materials, often both in Spanish and in English, which were geared toward varying audiences. The target audience in general consisted of parents, grandparents, and infant caregivers. All together we reviewed over 25 different examples looking specifically at the images as well as the messages in the materials. One of the key components we were looking for were babies shown sleeping in the back sleep position along with specific text stating this message. We also were looking for a picture of a safe crib (or bassinet or pack-n-play) along with reference to sleeping in the same room with the baby. We also looked for messages specifically addressing the risk factors for sleep-related deaths, specifically overheating and smoking as well as the risks of bed sharing. Additionally, we looked for messages that promoted breastfeeding, tummy time, and pacifier use, three very important protective factors according to the American Association of Pediatrics recommendations (AAP 2011a; AAP 2011b). Interestingly, the only two categories

addressed by all the campaigns were the images and messages of babies sleeping on their backs as well as an emphasis on a safe crib.

There were a few campaigns that really caught our eye as we went through this process. The one campaign that stood out was the campaign in Baltimore, MD. Baltimore had one of the highest IMRs in the country in 2009 when they developed their campaign, B'more for Healthy Babies (BHB), with the tag line "Every Baby Counts on You" (City of Baltimore Health Department "BHB"). Their campaign was the only one among all of those that our team reviewed that included a personal narrative from a mother whose baby died in their educational public messaging campaign. Today their website states that BHB remains "An innovative initiative to reduce infant mortality in Baltimore City through programs emphasizing policy change, service improvements, community mobilization, and behavior change" (City of Baltimore Health Department, BHB). Furthermore, since their safe infant sleep campaign has started, "Infant mortality has decreased by 28% since the launch of the initiative, from 13.5 in 2009 to 9.7 in 2012; the disparity between white and black infant deaths decreased by almost 40% during same time period" (City of Baltimore Health Department, BHB). Overall, they state that their campaign "has helped reduce the infant mortality rate in Baltimore City to its lowest point ever: 9.7 deaths per 1,000 live births (2012)" (City of Baltimore Health Department, BHB).

On the other hand, Milwaukee, WI, tried a different approach, using negative messaging and scare tactics, which eventually backfired after national public outrage. Their initial campaign efforts, like Baltimore, were in response to high numbers of sleep-related infant deaths. In Milwaukee, "Between 2006 and 2009 there were 89 infant

deaths related to SIDS, SUID, or accidental suffocation. Of these 46 (51.7%) infants were sleeping in an adult bed at the time of their death” (Milwaukee Health Department, Safe Sleep Campaign). The first image from their campaign in January 2010 was an adult bed with a headboard that looked like a tombstone, or grave marker, with the text “For Too Many Babies Last Year, This Was Their Final Resting Place” with the sub-text stating “The safest place is in a crib” (City of Milwaukee Health Department, Safe Sleep Campaign). Then in July 2010 they had an outdoor mattress campaign with actual mattresses placed sideways and displayed around the city with the outline of a baby painted in orange covered in various messages about the dangers of sharing a bed with a baby. Some of the text used was “It’s Time to Wake Up to the Dangers of Sleeping With a Baby Here,” “Babies Who Sleep Here Don’t Always Wake Up,” and “Imagine How Many Babies Would Still Be Alive if They’d Slept in a Crib” (City of Milwaukee Health Department, Safe Sleep Campaign). It was not until later in their campaign that they started to garner national attention. In November, 2011, their campaign included images of both White and Black babies sleeping on their stomachs or their sides in an adult bed surrounded by bedding and pillows alongside a butcher knife nearly the size of the baby. The tag line read “Your Baby Sleeping With You Can Be Just As Dangerous” (City of Milwaukee Health Department, Safe Sleep Campaign). There was an overwhelming negative response to these scare tactic ads, and the butcher knife pictures were eventually pulled. They then went in July, 2012, with a much more positive message showing both Black and White infants in a safe sleep environment and position with the text mapped onto the tight fitted crib sheet underneath the infant that read “Babies Should Always Sleep in a Crib” (City of Milwaukee Health Department, Safe Sleep Campaign). One of

the consistent components of the Milwaukee safe sleep campaign was the subtext in all the ads that stated, “If you can’t afford a crib, please call [...],” which was a telephone number for the Milwaukee Health Department, indicating there were resources to distribute infant sleep items, which I will also discuss in relation to Project Baby Springfield’s process later in this chapter of the dissertation (City of Milwaukee Health Department, Safe Sleep Campaign).

Preliminary Efforts Prior to PBS Safe Infant Sleep Campaign

Interns

It is important to note that PBS was able to attract and retain help from talented college interns, whose contributions in the summers prior to (2011 and 2012) and during (2013) the campaign were integral to all of PBS’s outreach efforts and successes. The recommendations garnered from the intern’s preliminary research in 2011 were integral to PBS’s future efforts. Their findings and recommendations helped to shape and lay the groundwork for PBS’s early work on safe sleep in 2012, and for the development and implementation of the actual safe infant sleep campaign in 2013.

During the summer of 2011, under the supervision of Dr. Balder, the interns conducted a variety of focus groups through many social service agencies serving young parents. The focus groups were done in both Springfield and Holyoke, Massachusetts. The participants were mostly young parents and primarily female. Following their work over the course of that summer, the interns reported back to the PBS team on their findings and recommendations. Additional details related to these recommendations will be discussed further in the data analysis section in Chapter 5 of the dissertation.

Focus Groups

The two PBS undergraduate summer 2011 interns conducted several focus groups with young parents throughout Springfield during the summer of 2011. At the end of their internship, one of their main recommendations was for PBS to conduct more focus groups across a broader audience. At the same time, there was discussion in safe sleep circles regarding the role of grandparents and/or caregivers who, in the African-American community, are more likely to have a significant role in the care of their grandchildren. Given this recommendation from the 2011 summer interns, PBS decided to lead additional focus groups during the summer of 2012 to discuss infant sleep with parents and grandparents in the African-American community in Springfield.

Subsequently, PBS chose to hold focus groups within the Mason Square neighborhood of Springfield, a largely African-American neighborhood yet increasingly Latino/a as well in recent years. PBS had many contacts within the Mason Square neighborhood, so securing locations to hold the focus groups was easy. Remember also that PBS had specifically selected the Mason Square neighborhood area given that it was one of the areas PBS had previously identified as having higher rates of infant death from the pushpin maps, as discussed earlier in this chapter.

PBS's plan was for one focus group to be specifically for grandparents, and another for parents from a range of ages. When only women signed up for the parenting focus group, PBS attempted to plan another focus group for fathers. Unfortunately, PBS was unsuccessful in recruiting participants for a focus group among fathers. This speaks to many issues regarding male involvement, which interestingly was one of the stated goals to emerge from the City of Springfield Maternal and Child Health Summit referenced earlier in this chapter. I do not believe that men do not want to be involved,

but that it is much more complex than that. I would assert that it has much to do with the way in which we have constructed masculinity within U.S. society, which is even more narrowly constructed for men of color, especially for Black and Latino men (Tough Guise 1999). One additional potential challenge could also be work schedules and hours, especially among working families, where many men have more than one job to help provide for their families.

Another, more structural challenge, is the way in which issues related to pregnancy and child rearing are constructed in U.S. society. These are areas that are often seen or talked about as women's issues or roles solely for women. This is evident simply by looking at who sits on the PBS team. Four men sit on the PBS team, and only 2 of them are regularly involved, one of whom is Dr. Balder. The other 2 are more peripherally involved given their multiple professional responsibilities, but not at all for lack of interest or commitment to children and families.

It is important to note that there are several men's groups and organizations in Springfield. One in particular with whom PBS has tried to build a partnership is MOCHA, the Men of Color Health Awareness group, funded by MADPH and run through the Springfield YMCA. The group's primary focus has been on raising awareness among Black men of prostate cancer, which is disproportionately higher in the Black community. MOCHA members often stopped by the PBS table when both groups were tabling at the same health fair or community event, but efforts at collaboration went nowhere. Sadly, this was just not the case with MOCHA, but in many attempts by PBS to network and join together with other groups and organizations in Springfield.

The PBS focus groups among grandparents and parents in Springfield were significant in that they gave PBS insight into what people think and know about infant sleep, and the answers to what people do, and why they do what they do, when it comes to infant sleep. I led the focus group among the grandparents, which took place at the Baystate Mason Square Neighborhood Health Center on a summer evening in June, 2012. Our graduate intern and I led the parent focus group, which took place during the evening hours the following week at the Mason Square Health Taskforce Offices at the Dunbar YMCA in Mason Square. PBS had received the small stipend of Target gift cards from the MADPH gift card stipend, so each participant received a 20\$ gift card for his/her participation. Additionally, PBS was able to buy snacks and beverages with the gift cards to Target for the focus group participants.

Two key women from the African-American faith-based community answered PBS's request to recruit participants. Each of the women, who were parents and grandparents themselves, also participated in the grandparent focus group. One of them also participated in the parent focus group. Together there were 10 participants in the grandparent focus group, ranging in age from 45 to 78 years old. Nine of the participants were female, and 1 was male. Nine participants identified as African-American and 1 as White. There were a total of 8 participants for the parent focus group, ranging in age from 20 to 39 years of age. All of the parent focus group participants identified as female and as African American. The findings from the focus group will be discussed in chapter 5 of the dissertation in conjunction with the quantitative data gathered from the PBS survey administered at the Community Baby Shower (CBS) just before the focus groups took place.

Community Baby Shower (CBS)

Every year around Mother's Day, the Maternal and Child Health Commission (MCH) of Springfield holds a Community Baby Shower (CBS) at the Commerce High School cafeteria. This event has been taking place since the 1990s, and is free to the public. It is geared specifically toward pregnant mothers and their partners/families as well as to new parents. There are a variety of informational tables set up around the cafeteria primarily from local agencies, organizations, and providers. PBS had a table each year, and in 2012, I volunteered to cover the table. Dr. Balder always volunteers in the kitchen area each year, but also helps out at the information table as he is able. Other team members were also at the event, but staffing the table specific to their job with a particular organization, provider, or agency.

Given that PBS's goal during 2012 was to start gathering background information for our safe infant sleep effort, the team decided to use the CBS as an opportunity to gather information. Subsequently, Dr. Balder, a few other team members, and I developed a quantitative anonymous survey in both English and Spanish that parents, or parents to be, could fill out regarding infant sleep position and environment (Appendix 1). Given the small stipend from MADPH for the focus groups on safe sleep, we were able to use some of the Target gift certificates as a raffle prize given that the survey was specific to safe infant sleep. Anyone who filled out a survey was entered into a raffle for a one hundred dollar gift certificate to Target. This was a large incentive, and as a result PBS received 62 completed surveys by the end of the event with respondents ranging in age from 15 to 49. Fifty-six of the survey participants identified as female and six of the participants identified as male. Twenty of the participants self-identified as African-

American, seven as White, thirty-two as Latino/a, two as Native American, and one self-identified as Biracial (without indicating any particular racial/ethnic groups).

I then was in charge of analyzing this data, and summarizing it for the team. I was also invited to the MADPH offices to present PBS's findings to the state safe sleep taskforce, which I was also a member of along with two other PBS team members from their respective agencies. I was invited to join this taskforce by the same fellow PBS team member who worked for the MADPH and had secured the stipend of Target gift cards for PBS's safe infant sleep efforts. The preliminary data gathered from the random sample of CBS attendees in conjunction with the focus group results together helped shape PBS's safe infant sleep educational and outreach planning efforts in 2013 once PBS received its grant funding from the March of Dimes and The Children's Miracle Network at Baystate Children's Hospital.

PBS Safe Infant Sleep Educational Outreach Campaign

In late summer 2012 PBS applied for and received funding specifically for safe sleep education and outreach for fiscal year 2013 from the March of Dimes of Massachusetts and the Children's Miracle Network through Baystate Children's Hospital in Springfield. PBS learned of these funding opportunities from direct connections within each of the funding organizations. Dr. Balder knew about the Children's Miracle Network Funding through working at the Baystate Neighborhood Health Center. He put together the application, for which PBS was later awarded \$15,500.00. PBS learned of the March of Dimes funding opportunity from a member of the March of Dimes MA office who sat on the PBS team. She told the team about the potential funding opportunity, and gave us the information for the request for proposals (RFP). Several

PBS team members worked together on the grant application for the March of Dimes. There were communication gaps between the March of Dimes, SDHHS, and PBS, which nearly cost PBS the grant. In the end, PBS was eventually awarded a grant of \$8,000.00 from the MA chapter of the March of Dimes for its safe infant sleep efforts.

As a result of these grants, PBS was able to hire a quarter-time, ten-hour per week, project coordinator for 2013, a position for which I was subsequently hired. Additionally, PBS was able to contract with Verdant Multicultural Media to develop various visual and print messaging on safe infant sleep for the educational and marketing campaign to be rolled out in 2013.

PBS had many successes during 2013 while engaging in its safe infant sleep efforts in Springfield. Following the recommendations of our summer 2011 undergraduate interns, who identified the need for a social media presence, PBS created a Facebook page, which was used as a platform to discuss safe infant sleep (www.facebook.com/safeinfantsleep). The link to the PBS Facebook page also served as the website link on any PBS print material. Additionally, our summer 2013 undergraduate intern and I worked together to create a PBS tri-fold brochure in both Spanish and English that gave an overview of PBS in addition to information specific to safe infant sleep (see Appendix 2). She and I also created a resource list order sheet that any community organization, agency, or provider could fill out for PBS to then send along materials on safe infant sleep as well as pre-pregnancy, contraception, pregnancy testing, and pregnancy related information and resources.

PBS was able to do a considerable amount of outreach within the Mason Square neighborhood more specifically, but also within the greater Springfield community. PBS

connected with a variety of community organizations and social service agencies, along with the provider community, in its safe infant sleep outreach efforts. PBS was able to attend and table at numerous community and health events around the city in order to connect with as many community members as possible. At these events PBS was able to talk directly to community members as well as providers. PBS was also able to distribute the newly created PBS brochure as well as a variety of safe infant sleep materials (brochures, handouts, door knob hangers), which PBS was able to receive for free from the NICHD. These safe infant sleep materials were in both English and Spanish. Additionally, there were materials on safe infant sleep directed specifically to the African-American community, for both parents and grandparents.

PBS was also able to develop a PowerPoint presentation specific to healthcare and social service providers, and team members subsequently gave multiple presentations among a variety of agencies and providers specific to safe infant sleep. Through an increased presence at various events, PBS was able to recruit new team members to join the team, but efforts to recruit youth, young parents, and community members outside of the provider community did not occur.

At the end of 2013, with the remaining grant money, PBS was able to purchase 35 Pack 'n Plays. PBS planned to develop a small "Pack 'n Play" distribution pilot program during 2014. As the coordinator in 2013, I did some of the initial groundwork for this, but this was not part of the 2013 campaign, and the future coordinator took on this project.

Lastly, following the success of its efforts in 2013, PBS was able, for the first time in its history, to secure funding for 2014 from SDHHS for the ten hour a week

coordinator position. I left the coordinator position at the end of the safe infant sleep campaign in 2013 to work on my dissertation. Our former summer 2012 graduate student intern, a doctoral student in Public Health at UMass-Amherst, assumed the role as the new coordinator for 2014. While writing this dissertation, I learned that SDHHS cut the funding for the position for 2015 to five hours per week, and eliminated it altogether starting in 2016.

PBS Efforts Beyond Safe Sleep

It is important to note that, beyond the specific issue of safe sleep, PBS is focused on pre-pregnancy, pregnancy, and birth outcomes as a whole as they relate to race, racism, and equity. Prior to the funding opportunities for PBS's safe infant sleep campaign, I participated, along with other PBS team members and community partners, in applying for a grant from City MatCH in order to address the racial equity issues around maternal and child health in Springfield. PBS was unsuccessful in securing that grant opportunity, but it does demonstrate an effort to systematically address and acknowledge the reality of racial inequity in Springfield as it pertains to pre-pregnancy, pregnancy, and birth outcomes.

Additionally, during my tenure as PBS coordinator in 2013, PBS held a community event during Public Health Month in April of 2013 specifically addressing racial inequity and birth outcomes. PBS planned the community conversation event at the Baystate Mason Square Neighborhood Health Center, in which the documentary *When the Bough Breaks* (2008) from the Unnatural Causes documentary film series was shown. The film highlights the work by two neonatologists from Chicago who look at the racial inequity of LBW and prematurity among African-American mothers. The film

viewing was then followed by a discussion addressing the issues of race, racism, and equity among attendees. PBS actively sought opportunity to continue this type of outreach and engagement within the Springfield community, whether with community members, agencies, or providers.

CHAPTER 5

DATA ANALYSIS

When it is a matter of telling the truth and serving the victims, let unwelcome truths be told. Those of us privileged to witness and survive such events and conditions are under an imperative to unveil – and keep unveiling – these pathologies of power.

(Farmer 2005:22)

Following the groundwork laid by PBS's summer 2011 undergraduate interns, PBS sought to gather some base line quantitative and qualitative data on infant sleep position and location among members of the Springfield community. At the time, PBS had not secured any grant funding, but did have the stipend of Target gift cards from the MADPH to use for its safe infant sleep work. As such, PBS's all volunteer team continued to trudge ahead with plans to address safe infant sleep in Springfield. The work was done piecemeal, but little by little the team was able to compile data to inform its efforts. Quantitative data specific to infant sleep practices was gathered via an anonymous survey administered by PBS at a Community Baby Shower in May 2012. Subsequent qualitative data was gathered through a series of two focus groups held by PBS in June 2012 with grandparents and mothers from the Springfield community.

With an average annual attendance rate of 400 people, The Community Baby Shower (CBS) held each spring at Commerce High School in Springfield provided the best starting place for PBS to attempt to gather this preliminary quantitative data from the attendees. In fact, a study that evaluated community baby showers in Kansas and their efforts to promote safe infant sleep showed that the venue can provide an excellent opportunity to reach a large number of individuals. In their study, just as in Springfield, they specifically sought to engage with members of the African-American community

where infant deaths were disproportionately high in order to understand what people knew about safe infant sleep as well as how they were putting their infants to sleep (Ahlers-Schmidt et al. 2014).

PBS had a vendor table at the CBS event, and held a raffle for a \$100 gift card to Target from the MADPH funding for any current and expecting parents in exchange for completing its anonymous survey on infant sleep. As mentioned in Chapter 4 of this dissertation, 62 individuals filled out the surveys, ranging in age from 15 to 49. Fifty-six of the survey participants identified as female and six of the participants identified as male. Twenty of the participants self-identified as African-American, seven as White, thirty-two as Latino/a, two as Native American, and one self-identified as Biracial (without indicating any particular racial/ethnic groups).

Also, as addressed in Chapter 4, the per capita income for employed individuals in the city is \$18,400, just over half the per capita income for MA (\$35,000), and significantly less than the national per capita income level (\$28,000) (U.S. Census Bureau 2013). Additionally, 27% of individuals in Springfield live below the poverty level, nearly double the state (10.7%) and national rates (14%) (U.S. Census Bureau 2013). Thus, it was not surprising to find that a majority of the 62 survey participants indicated that they received some form of public assistance.

In fact, 51 of the participants indicated that they received assistance from the Women, Infants, and Children Nutrition Program (WIC), which provides vouchers to be used to purchase nutritionally approved items for the mother and her child(ren). WIC is a free nutrition program designed to provide support for women and children up to the age of five. WIC provides the vouchers for healthy foods, nutrition education, and

breastfeeding support for families. Additionally, forty-two participants indicated that they received Supplemental Nutrition Assistance Program (SNAP) benefits. SNAP is the largest program nationally that provides a safety net against hunger. The program offers nutrition assistance to millions of eligible, low-income individuals, and families throughout the U.S.

Thirty-eight of the female participants answered yes to breastfeeding their baby, indicating an average of 68% who breastfed or planned to breastfeed their baby. Despite being a small sampling, this does correlate exactly with the state data presented in Chapter 4, where on average 68% of mothers breastfeed or had plans to breastfeed in Springfield (MADPH 2013). This is a low percentage when compared to the state as a whole. In fact, Springfield has the third lowest percentage of mothers who breastfeed at discharge from the hospital after birth, or with plans to breastfeed, among the 30 largest communities as compared to the state rate of 82.9% (MADPH 2013). Among the 18 survey participants who self-identified as African-American and female, 11 (61%) answered yes to breastfeeding or that they had plans to breastfeed their baby when born, which is slightly lower than the overall rate (68%) among our survey respondents.

Given this overall low rate of breastfeeding in Springfield, several PBS team members expressed their disappointment and frustration that an infant formula vendor was allowed to table at the CBS event in 2012. The same vendor was allowed to table in 2013 and 2014, despite these critiques, which were made known to the CBS planning committee by members of PBS as well as other agencies and organizations. The CBS committee did add language to the vendor guidelines in 2014 stating, “Please remember that activities and information must be aligned with Maternal Child Health mission

statement” (CBS letter to vendors 2014). The letter further highlights the MCH mission statement, which is,

to promote a city-wide system for coordinating maternal and infant care that is culturally relevant and family centered with comprehensive services to promote health, prevent illness or death and optimize infant growth and development (CBS letter to vendors 2014).

The formula vendor, however, was still present with a table at the event in 2014. PBS did have a table at the 2015 CBS, but I was unable to attend the event, and I have been unable to confirm if the vendor was present or not at the baby shower.

The issue of breastfeeding remains a significant issue in Springfield in general given the overall low rate. Research has shown that this can be a challenge particularly within African-American communities, where efforts to promote breastfeeding run counter to the belief that formula is better (Nommsen-Rivers et al. 2010). Breastfeeding is not only the most nutritional option for the baby, barring special circumstances, but it is also a protective factor against SIDS (AAP SIDS Taskforce 2011a, 2011b). There are very few anthropological studies on breastfeeding and the African-American community. Those studies that exist are primarily from physical/biological anthropologists, similar to the work on infant sleep, which often address the issue from an evolutionary perspective. I am not undermining the importance of this perspective, but want to draw attention to the gap in the cultural/medical anthropological literature on this important issue. Further research is imperative to the continued work and discussion on these important issues within the Black community in the U.S. (#BlackLivesMatter N.d.).

One of the first questions on infant sleep that the PBS survey asked was specific to infant sleep location. Safety-approved sleep spaces for infants include an up to date full-sized crib, bassinet, or a Pack-n-Play. Guidelines for safety-approved sleep items can be found on the U.S. Consumer Product Safety Commission (CPSC) website, an important resource given that the guidelines change over time. For the PBS survey question about infant sleep location, four participants indicated that they use a Pack-n-Play, and eighteen participants said they use a bassinet. Thirty-seven of the participants indicated that their baby sleeps in a crib.

Room sharing was common among these 59 participants who indicated their baby slept in a crib, bassinet, or a Pack-n-Play. Indeed, 49 out of these 59 participants (83%) stated that their baby's crib, bassinet, or Pack-n-Play was in the parents' room. Among the 3 participants who did not indicate their baby slept in a crib, bassinet, or Pack-n-Play, 2 participants indicated that they bed shared, stating that the baby slept with them in their bed. The other participant indicated that the baby slept in a toddler bed. The age of the child for this response is not known, which may mean the child was older, or that it is in fact an infant sleeping in a toddler bed. Overall, this information was significant in demonstrating that room sharing is prevalent among our respondents, with more than 80% of participants indicating that they room shared with their infant. This correlates with the AAP SIDS Taskforce (2011a) recommendations, which emphasize room sharing with an infant, but note explicitly that the infant sleep on his/her own sleep surface (AAP SIDS Taskforce 2011a). This is also significant because room sharing is seen as a protective factor against SIDS (Ball 2009).

One of the things that stood out to PBS team members was that, among the 37 participants who indicated that the baby slept in a crib, 28 (76%) indicated that they use bumper pads (bumpers) in the crib. This piece of data was particularly revealing, demonstrating that bumper pads are still quite common in baby's cribs. One need simply look at any gossip magazine that highlights celebrity nurseries to see that almost always bumpers are present in addition to other items in the crib. Joyner and colleagues (2009) published a study evaluating infant sleep environments in magazines that were targeted to women of childbearing age. They found that more than two-thirds of the images of infant sleep environments were not consistent with the AAP recommendations (AAP SIDS Taskforce 2011a, 2011b; Joyner et al. 2009).

One example of this can be seen in the recent blog post for Pottery Barn Kids. While engaged in this dissertation research, I joined the Association of SIDS and Infant Mortality Program's (ASIP) online listserv in order to observe the ongoing conversations among the professional community members. According to their website,

The ASIP SUID IM listserv is a communication tool for SUID and infant mortality [IM] professionals. The goal of the listserv is to engage physicians, researchers, nurses, government workers and other SUID/IM stakeholders in discussions related to their work and thereby build a vibrant nationwide community of colleagues (ASIP, About Us 2015).

While writing this dissertation, one of the listserv members posted a comment in reference to these conflicting images about safe infant sleep in Pottery Barn Kid's June blog post. The blog highlights the nursery the Pottery Barn Kids designers created for Ayesha and Stephen Curry, who were expecting their second child (Pottery Barn Kids

Editors 2015). Stephen Curry was the National Basketball Association (NBA) MVP during the 2015 NBA finals. His daughter, Riley gained popularity outside of the sports world with her comments while sitting on her dad's lap during the after game press interviews. The blog photographs show the crib created for the Curry's by the Pottery Barn Kids designers which includes bumper pads and loose bedding. The crib is described in the blog as follows, "The focal point of the nursery is our Blythe crib. We dressed this classic crib with beautiful, soft bedding that we hope the newest member of the Curry family has many, many sweet dreams in" (Pottery Barn Kids Editors 2015).

Additionally, while engaged in this dissertation research, I would frequently pay attention to store displays of infant sleep environments. Target stores seem to follow the AAP SIDS Taskforce (2011a, 2011b) recommendations, although I do not know if this is intentional, as I have never observed anything but an empty crib with a tight fitting sheet over the mattress at their various stores in both MA and while traveling in MN. I have twice observed, once in MA, and another time while traveling in MN, both at Babies 'R Us stores, crib displays with bumper pads and blankets. This is also true for all Pottery Barn Kids catalogs and online photo displays. From a marketing standpoint this makes sense. The store is in the business of making money, and it makes sense to sell not just a crib, but all the accessories too.

Bumper pads would be included in this category, as they pose a potential risk for suffocation for a sleeping infant. However, it is important to note that the AAP SIDS Taskforce (2011a, 2011b) recommendations do not explicitly state not to use bumper pads in cribs, so this may be confusing for many parents. The AAP SIDS Taskforce

(2011a, 2011b) recommendations state, however, to “keep soft objects and loose bedding out of the crib” (1031).

The use of bumper pads (as well as blankets) speaks to the desire among parents to provide comfort and safety to their infants. As mentioned earlier in the literature review in Chapter 2 of the dissertation, one study by Ajao and colleagues (2011) among African-American parents found that regardless of socio-economic status and level of education, the parents’ indicated that they used soft bedding and/or soft objects primarily for the purposes of infant comfort and safety, and secondarily for aesthetics. This study demonstrated that many parents had the perception that soft bedding and bumper pads in a crib would help keep their infant safe, when in reality there is an increased risk of SIDS, accidental suffocation, entrapment, or strangulation from these items when placed in a crib with an infant (Ajao et al. 2011; Hauck et al. 2003; Kemp et al. 2000; Thach et al. 2007).

Each of the focus group conversations started off by asking the participants how they spent time with their families in order to get people talking and to create a conversational atmosphere. When we talked about how they spent time with their grandchildren or great-grandchildren, some of the grandparent participants indicated that they babysat or cared for their grandchildren. One participant said she babysat at the child’s home. She indicated that the baby slept in a crib, but that the crib had bumper pads. This participant also indicated that the baby slept with a stuffed lion like Simba from *The Lion King*. Most of the participants indicated that the children came to their home. In only one of these instances did a grandparent indicate that a crib was present in their own home (Grandparent Focus Group, June 20, 2012). This is understandable, yet

is, indeed, an important reminder that the message needs to be comprehensive. Not only do safe infant sleep messages need to be geared to implementing safe infant sleep practices for infants in their own homes, but also at the homes for those who care for them.

The two most salient themes in the focus group's conversations were the desire to provide safety and to provide comfort for an infant sleep environment. One participant explicitly stated this, "[...] Most people will – especially most women who – I think every woman loves to have their children and want them safe" (Grandparent Focus Group, June 20, 2012). One of the participants stated that, when she watched her seven month old granddaughter, that the granddaughter slept in her grandmother's bed. She described in detail how she made the bed in preparation for the baby to sleep. She said,

I put a blanket over the quilt, the covering, and then take two pillows, one on each side of her. And the headboard is cushiony too. So, that's what we do. We put her in the middle of the bed, with two pillows, so she won't roll off (Grandparent Focus Group, June 20, 2012).

Another grandmother said whenever she was babysitting that,

I would make a pallet on the floor. And they always slept on their backs. I would have some blankets. I would put several blankets under there, kind of make it cushiony. And I don't put anything around it. They'll stay in one place (Grandparent Focus Group, June 20, 2012).

The survey data also revealed not only the presence of blankets, but also soft objects in the baby's sleep environment. Forty-six of the survey participants indicated

that their baby slept with a blanket. Twelve indicated that their infant slept with a pillow. Three indicated that the baby slept with stuffed animals. When broken down by race and ethnicity among the PBS survey participants, 44 of the combined 52 (85%) African-American and Latino identified respondents indicated they used blankets, pillow, or stuffed animals compared to only 4 of the 7 (57%) White identified respondents. This correlates significantly with the NISP study findings, which found that non-Hispanic Black as well as Hispanic infants were more likely to have bedding (blankets, comforters, quilts, pillows, soft objects, etc.) than non-Hispanic White infants (Shapiro-Mendoza et al. 2015). As discussed in the literature review in chapter 2 of this dissertation, all of these items are considered hazardous when placed under the infant or loose in the infant sleep environment, increasing SIDS risk by 5-fold, and up to 21-fold when the infant is placed face down on his/her stomach for sleep (Hauck et al. 2003). This information was particularly helpful to PBS knowing that soft bedding and objects are a part of many people's routines, and the importance of engaging in conversations about them with parents, grandparents, and caregivers.

Despite the AAP SIDS Taskforce (2011a, 2011b) recommendations to “keep soft objects and loose bedding out of the crib,” it is important to note that most parents are not likely reading these recommendations (2011a:1031). If the child's health care provider, namely the child's pediatrician, is having this conversation about infant sleep location, position, and environment, then the parents are likely to get this information. However, if their pediatrician is not having a specific conversation around sleep location, position, and/or environment, then parents are likely getting the information on their own accord. This could come in many forms – from other people, friends and family

members, as well from other sources – magazines, television, movies, advertising, store displays, etc. This can clearly be a challenge because there are often conflicting messages between what the parent is told, by whom, and what infant sleep environments they see displayed in various stores and in magazine pictures. This speaks to the need for clear information and consistent messaging, but it is complicated in a capitalist society where there are competing interests between safety and profit. Thus, the pediatrician's role is both integral and essential to effectively communicate important information to parents regarding infant sleep position, location, and environment.

In fact, as mentioned in Chapter 2 of the dissertation, research has shown that there is a correlation between receiving information about infant sleep and infant care practices, and trusting that information from said physician in order for parents to subsequently follow that particular advice (Colson et al. 2006, 2009, 2013; Robida and Moon 2012; Von Kohorn et al. 2010). Additionally, the study by Gaydos and colleagues (2015) found that if the advice provided by other family members, even grandparents, contradicted the advice given by a trusted medical provider, the mothers in their study, recognizing that the familial advice may be out of date, were more likely to follow the provider's advice.

This correlates precisely to what the PBS focus group participants revealed in their conversations during the PBS focus groups held summer 2012. One of the focus group participants shared how she thought this topic of trust was “extremely crucial to [the] conversation” that night (Grandparent Focus Group, June 20, 2012). Earlier in the conversation she shared how she thought it was “generational” and “cultural” with regard to how things have changed over the years with how babies are put to sleep (Grandparent

Focus Group, June 20, 2012). She then went on to tell the story of her daughter's relationship with her pediatrician, who is also now, her granddaughter's pediatrician. She said,

“She trust him implicitly. So anything Dr. O’Reilly says is golden. So of course, he said, when he came to see the baby, when the baby was first born, his initial visit, and he’s doing this well-check, and he’s also talking to her – you should keep the baby on her back, you should put the baby in the crib, da-da-da-da-da, blah, blah, blah, blah. I really didn’t have too much [to say] except, like I said, with that cultural thing, she’s on her back. But [my daughter] was empowered [...] by him and the training that I stopped in my tracks. And the baby’s great, and healthy, and fine, and I never saw a problem or nothing. But I think that that trust that she has with her pediatrician or her provider, or whatever the case may be, I think that’s huge. So, whoever is passing along this information, people need to trust, or else it’s just a waste of time (Grandparent Focus Group, June 20, 2012).

One of the other participants then added how important it was for the information to come from a doctor that you have confidence in, and how important it is that people do not feel like they are being dictated to. He said,

That’s one of the way to address situations is to get the information to the pediatricians if they have one. Because most of the time, if they’ve gained some confidence in them, they will listen to them without feeling like you come in and you trying to direct, and you’re trying to order (Grandparent Focus Group, June 20, 2012).

Among the CBS survey participants, 58 of the 62 respondents said the safest place for the baby to sleep or nap is in a crib, bassinet, or Pack-n-Play. Only 4 participants stated that the safest place for a baby to sleep is in a bed with its parents. Three individuals circled both options as the safest place for a baby to sleep. It was clear that the majority of parents or expecting parents had the knowledge that a crib, bassinet, or Pack-n-Play is the safest location for a baby to sleep.

However, the reality of where a baby sleeps does not always correlate with knowing the safest place. In other words, there is often a gap in what people know and what they actually end up doing. This was further elucidated by the responses to the PBS survey which indicated that bed sharing was quite common among participants. Forty of the 62 (65%) participants indicated that the baby does sleep or nap in the bed with the parents. This is not uncommon, and correlates with the national data. As presented in Chapter 2, the National Infant Sleep Position (NISP) study found that 45% of all parents' bed shared with their infants at least some of the time (Colson et al. 2013).

Among the various racial and ethnic groups who participated in the PBS survey, Latinos were most likely to bed share, with 24/32 (75%) Latino respondents who indicated that they bed shared. Among our African-American respondents, 10/20 (50%) indicated that they bed shared. This is slightly higher than our White-identified respondents, with only 3/7 (43%) who indicated that they bed shared. The NISP study showed that non-Hispanic Black infants are more likely to bed share than any other racial or ethnic group in the study (Colson et al. 2013; Moon et al. 2010). While PBS's findings do not correlate with the NISP study, PBS had a significantly smaller sample size, and the differences between Black and White respondents does remain.

In addition to bed sharing, survey respondents indicated other sleeping locations for their infant. Two participants stated that the baby sleeps or naps with a brother or sister. Five participants stated that the baby sleeps or naps on the couch. Fourteen of the participants stated that the baby sleeps or naps in a car seat. And, 27 of the participants stated that the baby sleeps or naps on him/her. This information was particularly revealing to the PBS team in planning for its safe infant sleep educational campaign, given that studies have shown that car seats, sofas, recliners, as well as sleeping on or with an adult, increases the risk for SUID (Bartick and Smith 2014; Mathews et al. 2015; Rechtman et al. 2015).

With regards to sleep position, the PBS survey asked two questions. The first question asked what the safest position was for a baby to sleep, and the second asked about the position(s) one's baby actually slept in when sleeping or napping. PBS asked these two different questions in an attempt to tease out the difference between what is known and what is actually done in terms of individual behavior. About two-thirds of the parents or parents to be, 41/62 respondents, indicated that the safest position for their baby to sleep is on his/her back. Most seemed to know that it is not safe for a baby to sleep on his/her stomach, with only 4/62 indicating that it was the safest position. What was striking, however, was that 17/62 said that the safest position was for the baby to sleep on his/her side.

As for how babies actually slept, there was not always exclusively just one position. There was some overlap in responses, with respondents indicating one option or a combination of options for how their baby slept. Forty-one of the survey participants indicated that their baby slept on his/her back, which interestingly is exactly the number

of participants who indicated that this was the safest position for their baby to sleep. Thirteen participants indicated that their baby sleeps on his/her stomach, and 18 indicated that their baby sleeps on his/her side.

There was much conversation among focus group participants about how and where their children or grandchildren slept. Two of the grandparent focus group participants stated that their grandchild slept on an adult bed when the grandchild was at their home visiting. Another participant talked about how she made a sleeping space with several blankets on the floor, what she called “a pallet” (Grandparent Focus Group, June, 20, 2012). Two other participants said the baby slept in a car seat (Grandparent Focus Group, June 20, 2012).

When asked about sleep position, almost all of the parents said their baby slept on his/her back for sleep (Parent Focus Group, June 28, 2012). One of the mother’s said that, “She would prefer to fall asleep on her stomach, and I always flipped her on her back” (Parent Focus Group, June 28, 2012).

The responses differed greatly among the grandparents, however, where there was more talk of a baby sleeping on his/her side and/or stomach. One woman said, “We try to get her to sleep on her side, but she always goes back to her stomach” (Grandparent Focus Group, June 20, 2012). Another participant upon hearing this story then shared her own story. She said her seven month old grandson liked to go to sleep on his stomach. She attributed this to being similar across the different generations. She said, “Because it’s my grandson, he’s like his father. His father slept on his stomach” (Grandparent Focus Group, June 20, 2012).

The conversation about sleep prompted another grandmother to speak up. She talked extensively about her two different experiences with her two daughters and their babies around sleep location and position. She said that when her daughter first brought her granddaughter who was nine months old at the time of the focus group to her the house as a new baby that,

[She] laid her on her bed, kind of instinctually, and I was like, I cringed. I was like, I don't know if she's supposed to be sleeping on her bed. And so I wanted to say something, but then I said, no, I don't want to be like one of those grandmothers that, you know introduce some kind of fear, whatever, into my daughter. She's a new mother, and I'm a new grandmother, so we both like pretty terrified at this point. So anyway, I remember just kind of yielding to the fact that her, as her mother, her instinct and her intuition is going to supersede mine, just like I felt like when I gave birth to her, that it was just like that (Grandparent Focus Group, June 20, 2012).

She then talked about her other daughter and her other granddaughter, who was five months old at the time of the focus group. She said,

My grandbaby that's five months old, she sleeps on her stomach. And so, when I became a part of this committee, and was introduced to all of this information, I was like...! But when I went to my daughter and I broached the conversation, again, trying not to be panicky or anything like that, to bring any fear into it, [she] said to me, she was like, Mommy, I know, but the doctor told me, the doctor told me that it's better for [her] to sleep on her stomach, because [she] – what she does, she has like this buildup of saliva, and I think it's because of the way that

her jaw and things are formed, so she's always kind of – yeah, always drooling. And I mean massive amounts or whatever. And so, again, it was like, well, thank goodness I asked, and she told me, and so now I feel a whole lot better seeing her sleep on her stomach (Grandparent Focus Group, June 20, 2012).

All of the focus group participants talked about a variety of sleep positions – side, stomach, and back. As mentioned earlier, most mothers in the parent focus group said their babies slept on their backs. However, among the grandparents, there was no one conclusion or consensus among the grandparents in the focus group about how a baby should be put to sleep. Many participants did say, however, that they put the baby to sleep on his/her side, as an in-between alternative to placing the baby on his/her back or stomach to sleep, because of the conflicting and confusing information they have received over time regarding how to put a baby to sleep. One of the participants summed up this point during the discussion, which was accompanied by many a “yes” and “yeahs” from other focus group participants,

We know that it seems like every other year, or every five years, the so-called reports are saying, sleep on the stomach, sleep on the back, sleep on the stomach, sleep on the back. Just that and the other inputs. But, for the most part, because of that confusion. I used to put my kids to sleep on their side because of that confusion, and because of that fear for SIDS and so on and so forth (Grandparent Focus Group, June 20, 2012).

In fact, the reality of a baby dying during sleep and the fear of SIDS was very real among both focus group participants and one other interviewee. The male participant in

the grandparent group explained that he now put his children to sleep in their crib although he did not always do so. He told the story of his wife working nights, and that he had the baby in his care while she worked. He said,

I sleep hard. So once, I had one of my daughters, and I was sleeping, so I went to bed, and my wife walked in, and I was sleeping hard. And so I had rolled, and I...and I say, never. Never again. From then on out, it was crib. That's it, crib. Never. The only...I learned fast. Nothing happens. They're born, we had a crib ready" (Grandparent Focus Group, June 20, 2012).

One of the women from the parent focus group talked about a tragedy that happened in her own family a little over forty years ago. She said,

There was an argument with me and my mom. And I wasn't sure why until after I had our son. She said, because her and my other cousin was in a bed together. And my mom was a little bit chubbier, so wasn't the one that got stuck. But my aunt was the one that got stuck, and she died. So that's why she really didn't want...she didn't even want my son to have a crib. She told me, 'Bassinnet, if anything, and that's it.' I bought him a crib, but he hasn't slept in it, so... (Parent Focus Group, June, 28, 2012).

One of the grandparent participants shared with the group that she knew a woman from her church whose baby stopped breathing and had to perform CPR on the baby (Grandparent Focus Group, June 20, 2012). One of the mother's from the parent group said that when she was living at a hotel shelter another woman came running down the hall because her baby was not breathing after being placed face down on the hotel bed to

sleep. She said, “But just that experience... Now when I think about that experience, and her baby’s not breathing, and... and I’ll always remember that (Parent Focus Group, June 28, 2012).

This fear was also very real for another mother I met while engaged in this dissertation research project. She had a similar experience with her baby choking and turning blue. In fact, it turned out her daughter had Gastro Reflux, and was given reflux medication. She said the specialist never talked to her about sleep position or location at all. She also stated that she knew someone whose baby had died from this. She talked about how she was very aware of SIDS. She said, however, “A crib was not an option. My fears were outweighed by seeing her choke” (Personal Interview, August 9, 2014). She said, “I know my kid, and I know my situation. I agree with PBS’s [safe infant sleep] message, but that didn’t work in my situation” (Personal Interview, August 9, 2014). She shared that she chose to bed share in order to have her daughter right next to her. When I asked her about sleep and her conversations with her pediatrician, she said her pediatrician asked her if her daughter slept through the night at every checkup, but did not ask about where or how her daughter slept (Personal Interview, August 9, 2014).

Many of the participants spoke about keeping a watchful eye on their grandchildren stating, “When they would sleep in their crib, I will go watch them” (Grandparent Focus Group, June 20, 2012). Another confirmed this as well saying, “I know, I know, I still do that!” (Grandparent Focus Group, June 20, 2012). Another participant stated, “I want to make sure they’re alright” (Grandparent Focus Group, June 20, 2012). Another said, she wanted to make sure to hear that “they are sleeping and breathing” (Grandparent Focus Group, June 20, 2012).

There was a real fear of a baby sleeping on his/her back and choking among many of the participants. One grandparent expressed, “I’m afraid of them getting choked or strangled” (Grandparent Focus Group, June 20, 2012). One of the mother’s said, “My fear with that is like, if they are sick, or if something’s going on, and they vomit in their sleep, they’re facing a different direction, where it would come out” (Parent Focus Group, June 28, 2012). Another mother told a story of her baby having a cold and being congested. She said,

So it’s just like, continuing to be unable to breathe through his nose all the time, and it will scare me, because he was on his back. Because he would have congestion so badly, it would start to go down his throat, and then it would start to gag him – and then he’ll start choking. And he’d wake up in the middle of the night, choking and not being able to breathe. And it would scare me so badly. It’s like, oh, what do I do? And he still won’t sleep on his back. But he can’t breathe. And I was like, OK, I really thought, I’m a light sleeper. But what if it was a time, you know, my husband’s home. What if [he] was with him, and I wasn’t there, and he started to choke? Would he be safe like that?

(Parent Focus Group, June 28, 2012).

Whether the conversation was about how or where a baby slept, the two central themes that emerged from all of the conversations were those of infant safety and comfort. Interestingly, these were the exact themes that emerged in many of the qualitative studies among African-Americans that were highlighted in the literature review section of Chapter 2 of this dissertation. It was evident through all the

conversations highlighted here that people clearly wanted to do what was best to care and protect their children and grandchildren.

However, the gap in getting that information out and reaching all parents, grandparents, caregivers, and providers was the task that lay ahead for PBS in putting together its safe infant sleep educational campaign in 2013. PBS knew from the focus group conversations as well as the survey administered at the CBS that most people knew the safest way to put a baby to sleep was on his/her back. Yet, many still placed their baby to sleep on his/her side, and many bed shared. The PBS team had several conversations about whether or not to take a harm reduction approach or to take a hard line stance regarding its infant sleep message. A harm reduction approach would have entailed giving parents information about the best and safest way to sleep if they are going to bed share, but the PBS team decided against this. Instead, the PBS team decided to take a firm stance against bed sharing in its educational outreach campaign, adopting the talking points laid out in the AAP SIDS taskforce (2001a, 2011b) policy statement explicitly focused on safe infant sleep. While PBS was in the middle of this process in 2012, the MA state safe sleep taskforce, which I was asked to join, came out with clear recommendations that followed the AAP policy changes in 2011 of no bed sharing, no soft objects or soft bedding (MADPH 2012).

The 2012 focus group participants reiterated a point that also came through in the recommendations from the PBS 2011 undergraduate summer interns based on their focus groups with young parents, which was to use simple and clear messages in order to help clarify the often mixed or confusing messages parents and grandparents receive. One example of this is demonstrated in the use of the ABC's of safe sleep, which PBS

adopted in its brochure and print material and works in both Spanish and English. The letter A stands for alone, meaning the baby is his/her own sleep space, but in the same room as the parent or caregiver; the letter B stands for back, meaning the baby should be placed on his/her back for every sleep; and the letter C stands for crib, meaning a separate safety approved sleep space such a crib, bassinet, or Pack-n-Play.

Based upon their focus groups with young parents, PBS's summer 2011 undergraduate interns recommended that any messages that PBS utilize not use scare tactics, as exemplified in Milwaukee's example discussed in Chapter 4 of the dissertation. Another suggestion that emerged from both the summer of 2011 and summer of 2012 focus group participants was to keep the message positive and empowering to parents, grandparents, and caregivers. Lastly, another suggestion that was similar from the majority of focus group participants those two summers was that that PBS utilize the media in selective ways through various community outlets, which PBS did selectively through social media, print, radio, and television during the 2013 safe infant sleep educational outreach campaign.

As a result of PBS's collaboration with Natalia Muñoz and her company, Verdant Multicultural Media, PBS unveiled its safe infant sleep posters at our National Infant Mortality Awareness month event in September 2013 (see Appendix 3). PBS planned a baby shoe memorial event in honor of the infants whose lives are lost each year in Springfield. PBS received a volunteer donation of baby shoes from Savers, a local bargain resale store. The 21 pairs of shoes, representing the average number of infant deaths per year in Springfield, were displayed at the front of the room in City Hall where the mayor's office read a proclamation declaring September, 2013, as National Infant

Mortality Awareness Month in the City of Springfield. PBS received coverage in the local newspaper, The Republican, regarding the baby shoe memorial event. One of the long standing Springfield City Councilors, Bud Williams, was in attendance the day of the event, and was moved to make an additional declaration in later weeks to highlight and acknowledge the high rate of infant deaths in Springfield.

PBS's goal was to develop a safe sleep educational campaign in order to reach the largest number of community members and providers within Springfield. Verdant Multicultural Media worked closely with PBS to develop safe infant sleep posters in both Spanish and English with photos of local babies that were placed in and outside of PVTAs buses for a 3 month period in 2013 (see Appendix 3). Verdant Multicultural Media and her team also produced two public safety announcements (one in English and the other in Spanish) specific to safe infant sleep that depicted actual Springfield families and their infants in the videos. These videos were placed on PBS's Facebook page. PBS was also able to print and distribute laminated copies of the same posters that appeared inside the public buses to numerous provider and agencies to be placed in their waiting rooms and exam rooms in an effort to extend the message to providers and community members.

PBS sought to engage community members not only through social media and the bus posters, but also through print media, radio, and television. Dr. Balder, our summer 2013 undergraduate intern from Amherst College, Jessica, and I wrote an article about safe infant sleep that included a picture of the safe sleep poster from the bus in Point of View, a local newspaper specific to the African-American community in Springfield. I also wrote an article in Spanish, which along with the Spanish language version of the bus poster, was printed in two different local newspapers for the Latino/a community in

Springfield and the surrounding area, *El Sol Latino* and *El Pueblo Latino*. Dr. Balder and I did a radio show with the youth in Mason Square called The Gap Closer on WTCC 90.7 FM. Dr. Balder also did a short presentation on safe infant sleep position and a safe infant sleep environment which aired on Mass Appeal, a local news show on the NBC station in Western Massachusetts. I also did an interview on Connecting Point, a special topics program for our local PBS station. This aired during October 2013 specifically during Baby Loss Awareness Week, with October also being National SIDS Awareness Month. As a member of the Massachusetts safe infant sleep taskforce through the Massachusetts Department of Public Health, I was invited to Boston to present on the PBS safe infant sleep campaign and to talk about PBS's outreach efforts on safe infant sleep in Springfield.

PBS had many successes throughout its process, but there were also challenges that emerged. One of the primary challenges facing the PBS team was access to data, as the state data as well as the Springfield specific data (which also comes from the state) was 3 years behind. Thus, throughout this dissertation I have drawn on 2010 data, as that was the consistent data available for both local, state, and national data while I was writing.

Recent data for 2011 and 2012 for the state of Massachusetts as well as the city of Springfield was just released as I was finishing writing this dissertation. The data shows that the IMR for 2011-2012 for the state of Massachusetts was 4.2, yet the persistent two-fold inequities remain when the data is categorized by race and ethnicity. The non-Hispanic Black rate for 2011-2012 for the state was 7.9, whereas the non-Hispanic White rate was 3.5 (MADPH 2015; #BlackLivesMatter N.d.). For Springfield, the 2011 IMR

was 7.9, and the 2012 IMR was 3.8 (MADPH 2015). Despite this drastic reduction of 50% in the IMR between 2011 and 2012, Springfield still had the second highest IMR (7.0) among the 30 largest communities in the state of Massachusetts based on a three-year average for 2010-2012, with Pittsfield having the highest (MADPH 2015).

This is data that would have been beneficial in the PBS planning process for its safe infant sleep campaign, but it was not available until 2015. This demonstrated the impact of a three-year lag in access to data. The only current data PBS had access to during its planning process came from a team member from the Massachusetts SIDS Center in Boston, whose office would often receive notification of an infant death. She kept track of the infant deaths referred to her office for Springfield and compiled that information for the PBS team. This was essential information, and the only real time information the PBS team had access to while planning its safe infant sleep campaign. This team member retired in 2015, so PBS does not have access to the real time data anymore going forward.

Some of the other challenges encountered while engaged in the project work center around communication, collaboration, time, lack of resources, and competing agendas among different stakeholders. PBS found engaging with other community groups to be challenging especially due to time constraints and lack of resources (both people and material). Developing relationships outside of the communities and neighborhoods where PBS had begun its outreach was also challenging. This clearly speaks to the key role of gatekeepers and those cultural brokers within the community itself, the community organizations, as well as the agencies/providers serving those communities. There is a strong need to develop multiple connections, but in a resource-

limited environment where there are competing agendas, this has been difficult to overcome in a short period of time. Communication challenges arose, for example, in trying to make connections, or set up a meeting. One could send several emails and leave several voicemails, and never receive a response. Additionally, once contact was made, it was often weeks to get a meeting set up. In one instance all the leg work was done, and a key gatekeeper helped to set up a meeting where plans were agreed to, but all follow-up phone calls and emails after that initial meeting went unanswered.

One of the additional challenges of the PBS safe infant sleep campaign was that there was no funding to allow the team to do an evaluation of the campaign. PBS planned to incorporate an evaluation component as part of the Pack-n-Play Pilot Project that was to be launched in 2014 so as to start to do an evaluative process of the work PBS started in 2013. PBS's only evaluation tools came in the form of the quantitative data from the State, which, as I mentioned earlier, is 3 years behind the real-time data from the referrals to the Massachusetts SIDS Center, and PBS's own surveys and focus groups, which were summarized here. But there was no evaluation of the safe infant sleep educational campaign upon its completion.

One of the other challenges regarding PBS's efforts and its safe infant sleep campaign centers on the sustainability of the project and the campaign. Connections to outside funding organizations were integral to the safe sleep funding PBS received from the March of Dimes and the Children's Miracle Network at Baystate Children's Hospital as well as the local Community Health Network Association (CHNA). These connections were key factors in learning about funding opportunities, especially in a climate of decreased funding and limited financial resources. Following the success of

PBS's 2013 safe infant sleep campaign, The Springfield Department of Health and Human Services (SDHHS) promised to match the 2013 grant funding for the PBS coordinator position for 2014 so PBS could continue its work in Springfield. Although it took nearly a year for the funding to come in from SDHHS, the 2014 coordinator was PBS's summer 2012 intern, a graduate student in Public Health at UMass Amherst. PBS's efforts in 2014 and 2015 have been focused on prenatal care and access to care among mothers in Springfield. PBS continues to build its network, to keep its messages about safe infant sleep and pregnancy current, and to also maintain its social media presence through Facebook and Instagram. PBS received a small grant from the local CHNA at the end of 2013 to support more printing of PBS's safe infant sleep posters for continued distribution to any group, provider, or organization who wants to display them. Lastly, PBS continues to pursue other grant and funding opportunities for its work. As of 2015, SDHHS cut the funding for the coordinator position to 5 hours per week, and cut the funding entirely starting in 2016. Most recently, PBS has received some small donations from the local Kiwanis and Baystate Health Systems to continue its work in the Springfield community focusing on prenatal care.

CHAPTER 6

CONCLUSION

Through an anthropology committed to praxis, we can work to eliminate the present inequities in health and well-being.

(Anglin 1997:1368)

As I engaged in the research process and conclude this dissertation it was, and is still, evident that the issues surrounding safe infant sleep are complex and multi-layered. Bartick and Smith (2014) remind us that “No infant sleep environment is completely safe” drawing our attention to the subjectivity of the very notion of safety in the presence of many unknowns and various factors (420). Additionally, it is important to note, as Dr. Balder always reminds the Project Baby Springfield (PBS) team, that no nation has an infant mortality rate (IMR) of zero. However, what the research does reveal is that the United States (U.S.) as a whole has the highest infant mortality rate among all industrialized nations despite its overwhelming and disproportionate wealth as well as the availability of and access to a plethora of resources and advanced technology (CIA Factbook).

Furthermore, the cadre of scholarly research across social science, public health, and medical disciplines reveals that there are clear health inequities present among non-Hispanic, Black infants, whose infant mortality rates (IMRs) at the local (Springfield, MA), state (MA), and national (U.S.) level are consistently more than double the rates of non-Hispanic, White infants (MADPH 2013; Mathews and MacDorman 2013; #Black

Lives Matter N.d.). The impact of racial and ethnic disparities highlights a dire need to address the inequities facing African-American families in the Springfield community where this dissertation research was undertaken.

In fact, despite the fact that the local and national rate has continued to decline for both groups over time, it is important to note that this gap in IMRs between Black and White infants has been consistently two-fold throughout the past decade (MADPH 2013; Mathews and MacDorman 2013; #Black Lives Matter N.d.). Similar to the overall two-fold disparity seen in national infant mortality data rates between non-Hispanic, Black and non-Hispanic, White infants, when analyzing SUID/SIDS death rates alone, non-Hispanic, Black infants also have more than double the rate of death compared to non-Hispanic, White infants (Moon et al. 2004; Moon et al. 2010; #Black Lives Matter 2015).

What is also striking is that the racial gap remains across all educational and income categories, and has continued to worsen despite the decline in SIDS rates overall (Moon et al. 2004; Moon et al. 2010; #Black Lives Matter N.d.). This is significant given that, for most health outcomes in the context of the U.S., researchers are able to demonstrate a direct correlation between an individual's educational attainment and the individual's socio-economic status. However, as already established in Chapter 2 of this dissertation, this is not the case when it comes to infant mortality and birth outcome inequities. Indeed, a baby born to a non-Hispanic White woman who never graduated high school is more likely to survive infancy than a baby born to a non-Hispanic Black woman with a college degree (Braveman et al. 2010; *When the Bough Breaks* 2008; #Black Lives Matter N.d.).

Williams (1997) highlights that “These racial disparities in health are not new, but our understanding of the specific factors responsible for them is limited from both a scientific and a policy perspective” (322). Additionally, emerging science across multiple disciplines documents the lifelong impact of stress associated with racism is one of the most significant predictors of these racial health inequities (Lu and Halfon 2003; Williams and Mohammed 2013). These two principles, in addition to the theoretical and methodological perspectives of Critical Medical Anthropology (CMA) and Critical Race Theory (CRT), shaped this dissertation research project. Thus, this study began with an explicit understanding that race and racism play a role in shaping health outcomes for people of color in the U.S., and disproportionately so for African-Americans (Randall 2006; Williams 1997; #Black Lives Matter N.d.).

This dissertation sought to explore and analyze Project Baby Springfield’s efforts to address infant mortality within the City of Springfield, MA, through its educational outreach campaign focused on sleep-related infant deaths. As highlighted in Chapter 3 of the dissertation, this was an essential and necessary starting place for an intervention, given that between 2006 and 2011, when PBS was beginning to plan its outreach efforts, there had been a total of 34 sudden unexpected infant deaths (SUIDs) in Springfield. Twenty of the 34 deaths (nearly 60%) were associated with an “unsafe sleep environment” or an “unsafe sleep position,” with the majority of these deaths among African-American and Latino/a infants (MA SIDS Center 2014).

As this dissertation has established, there are behavioral and environmental factors that emerged from the scholarly research. These are also mirrored in the quantitative and qualitative data I gathered during this study. This data may help explain

some of the contributing factors for Black infant sleep-related death, namely, those related to the higher likelihood and frequency of bed sharing and the presence of various objects within the infant sleep environment among non-Hispanic, Black families. These factors emerged, however, not in the context of neglect, but in the context of the documented themes of safety and care for the infant specific to the infant sleep position and the infant sleep environment.

Some of these factors include: side sleeping, soft surfaces, loose bedding, overheating, smoking during pregnancy, environmental tobacco smoke (second or third hand), bed sharing, prematurity and/or low birth weight (LBW), young parental age, low parental educational level, and inadequate prenatal care in addition to African-American or American Indian, Alaska Native heritage (CDC, SIDS; Miller et al. 2011; Moon et al. 2004; Moon and Fu 2012; Trachtenberg et al. 2012). And, while these are plausible contributing factors to the higher rate of sleep-related causes of Black infant death in the U.S., there is no research that states definitively that these alone account for the higher rate of death among Black infants.

In addition to the behavioral and environmental factors, the scholarly literature and the theoretical and methodological frameworks of CMA and CRT also address the larger structural issues that impact people's lives and health. In other words, together they establish and elucidate that,

people develop their own individual and collective undertakings and responses to illness and to other threats to their well-being, but they do so in a world that is not of their own making, a world in which inequality of access to health care, the

media, productive resources (e.g., land, water), and valued social statuses play a significant role in their daily options (Singer and Baer 2012:40).

This is to say, that, while it is essential to recognize and address how and why one's personal and cultural beliefs impact one's individual behavior(s), there are other structural issues that also shape and impact those beliefs, choices, and behaviors.

The review of the literature across multiple disciplines speaks to the need for collaboration among practitioners from multiple fields as well as direct connections to cultural contexts. Trachtenberg and colleagues (2012) argue that more information is needed in the U.S. to tailor messages specific to the U.S. context. This was especially true in the anthropological literature, where there is a tremendous gap. Many of the anthropological studies on infant sleep are cross-cultural, however none addressed the historical, economic, political, and cultural context of race and racism in the U.S. specific to African-Americans (#Black Lives Matter N.d.).

PBS has sought to build upon the resources, information, partnerships, and its presence in the Springfield community, with the goal of closing the local educational gap, making a lasting and significant reduction in the infant mortality rates in the city, and to effectively and collaboratively address the challenges inherent in addressing racial health inequities, even among something as precious and vital as the survival of infants. Following the safe infant sleep educational campaign in 2013, PBS continued its outreach efforts in the Springfield community in 2014 and 2015, focusing specifically on the issue of prenatal care. Nothing, however, has been accomplished outside of PBS's efforts on safe infant sleep and prenatal care access to further address the Action Plan and

Implementation Framework (discussed in Chapter 3), which came out of the Maternal Infant Strategic Plan Summit held in June 2012 for the City of Springfield.

PBS and its partners developed this Action Plan and Implementation Framework in order to address the various factors impacting the poor birth outcome inequities in Springfield. However, no financial or material resources beyond the minimal coordinator funding provided by SDHHS in 2014 and 2015 have been allocated or ascertained by the city or the state.

This dissertation has demonstrated that PBS's focus on safe infant sleep made sense as a first step given the data and the funding opportunities available at the time. Scholarly research by Lu and colleagues (2010) also supports PBS's subsequent efforts in 2014 and 2015 to focus on and address prenatal care access as a way to address the racial inequities in birth outcomes. However, these efforts alone have not and will not close the racial health gap in birth outcomes (Lu et al. 2010).

Effectively reducing infant mortality, particularly within the African-American community in Springfield, will require an integrative approach to lifelong contributors to unequal health status as well as working to acknowledge and eradicate the racial inequities that exist (#Black Lives Matter 2015). Investments must be made to ensure that the infrastructure exists to decrease institutionalized racism and to support programs that identify and address racism and inequity. Smedley and Myers (2014) argue that "To tackle these challenges, policies must be crafted that mitigate the impact of racism on health at multiple levels of influence, ranging from public and individual awareness and education to school and residential segregation" (387). This requires a certain level of engagement for both researchers, individuals, and communities. It also requires a

willingness to have the necessary, albeit challenging, conversations. Therein lies the challenge for PBS and its efforts, for its resources and power is extremely limited.

This dissertation research project makes it abundantly clear that an approach to address, understand, and invest in community health must be applied to policy development in order to lower Springfield's IMRs and to close the gap in the racial health inequities. An applied critical medical anthropological approach and a critical race theory methodological approach both allow for a unique pathway to engage in research with the community, to develop innovative policy, and to an ongoing commitment to reflexive practice. Indeed, "Medical anthropology should exist for us both as a discipline and as a field of struggle. Our work should be at the margins, questioning premises, and subjecting epistemologies that represent powerful, political interests to oppositional thinking. It is, in short, the work of anthropology turned in upon ourselves, our own society" (Scheper-Hughes 1990:193). Thus, until we live in a society where all lives matter equally, my commitment to an engaged and critical anthropology will continue to focus on the issues affecting those who are most marginalized and vulnerable in our society. So, today, given the racial health inequities presented in this dissertation research project, I say unequivocally **Black Lives Matter**.

APPENDIX A

SAFE SLEEP INITIATIVE SURVEY, SPANISH AND ENGLISH

Survey, in Spanish:

**CUESTIONARIO DE LA INICIATIVA DEL SUEÑO SEGURO
PARA LA CIUDAD DE SPRINGFIELD, MA**

¿Usa una cuna, una "pack n play", o un moisés?

Sí No

Si, NO, porqué?

Si, A, B o C arriba, dónde se encuentra la cuna, el "pack n play", o el moisés? (por favor marque uno):
En su habitación En otra habitación

¿Dónde duerme/durmió su bebé la mayoría de noches? (por favor marque todos que correspondan):

- a.) Cuna
- b.) "Pack n Play"
- c.) Moisés
- d.) Otro (por favor explique aquí):

Si "A" (Cuna), se usa/usó protectores para la cuna?

Sí No

En el caso afirmativo, por favor explique aquí:

¿Hay algunas veces que su bebé se duerme/durmió en una de los siguientes? (marque todos que correspondan):

- a.) En su cama?
- b.) En la cama con un hermano o una hermana?
- c.) En un asiento de seguridad infantil?
- d.) En el sofá?
- e.) Encima de ti? (pecho, piernas, brazos)
- f.) Otro (por favor explique aquí):

¿Dónde cree que es el lugar más seguro para el bebé a dormir?

- a.) Una cuna, "pack n play", o moisés
- b.) En la cama contigo
- c.) En la cama con un hermano o una hermana
- d.) En un asiento de seguridad infantil
- e.) No importa, todos son igualmente los mismos
- f.) Otro (por favor explique aquí):

¿En qué posición duerme/durmió su bebé?

- a.) En su estómago (boca abajo)
- b.) En su espalda (boca arriba)
- c.) En su lado (cualquier)
- d.) Otro (por favor explique aquí):

¿Cuál cree que es la posición más segura para su bebé a dormir?

- a.) En su estómago (boca abajo)
- b.) En su espalda (boca arriba)
- c.) En su lado (cualquier)
- d.) Otro (por favor explique aquí):

¿Duerme/Durmió su bebé con cualquiera de los siguientes? (por favor marque todos que apliquen):

- a.) Manta(s) o Sábanas
- b.) Almohada(s)
- c.) Un animal de peluche
- d.) Otro(s) artículo(s) (por favor explique aquí):

Su Género: _____
Su Edad: _____
¿Cuántos niños tiene? _____
Su Raza/Etnicidad (por favor marque todos que correspondan):
Puertorriqueña/o
Dominicana/o
Guatemalteco
Mexicana/o
Otro (explique aquí):
¿Nació en un país distinto de los EE.UU.? SÍ NO
Si afirmativo, dónde? _____
¿Si mujer, amamanta/amamantó a su bebé? SÍ NO
Si afirmativo, por cuántos meses? _____
Recibe beneficios de WIC? SÍ NO
Recibe beneficios de SNAP? SÍ NO

Survey, English:

**SAFE SLEEP INITIATIVE SURVEY/QUESTIONNAIRE
CITY of SPRINGFIELD, MA**

Where does/did your baby sleep most nights?

(please circle all that apply)

- a.) Crib
- b.) Pack n Play
- c.) Bassinet
- d.) Other (please explain here):

If "A" (Crib), do/did you use bumper pads?

YES NO

If YES, please explain here:

If A, B, or C is circled above, where is/was the crib, pack n play or bassinet located?
(please circle one)

In your room In another room

Does/Did your baby ever sleep/nap in any of the following? (please circle all that apply)

- a.) In your bed?
- b.) In bed with a brother or sister?
- c.) In a car seat?
- d.) On the couch?
- e.) On you? (your chest, lap, arms)
- f.) Other (please explain here):

Where do you think is the safest place for your baby to sleep?

- a.) A crib, Pack n Play, or bassinet
- b.) In your bed
- c.) In bed with a brother/sister
- d.) In a child car seat
- e.) Any of the above are equally the same
- f.) Other (please explain here):

What position does/did your baby sleep?

- a.) On his/her stomach (face down)
- b.) On his/her back (face up)
- c.) On his/her side
- d.) Other (please explain here):

What do you believe is the safest position for your baby to sleep?

- a.) On his/her stomach (face down)
- b.) On his/her back (face up)
- c.) On his/her side
- d.) Other (please explain here):

Does/Did your baby sleep with any of the following (please circle all that apply)

- a.) Blanket(s) or Sheet(s)
- b.) Pillow(s)
- c.) Stuffed animal(s)
- d.) Other item(s) (please explain here):

<p>Gender (circle one): Male Female</p> <p>Your Age: _____</p> <p>How many children to you have? _____</p> <p>Your Race/Ethnicity (please circle all that apply): African American/Black Caucasian/White Latino Asian Native American Other (please explain): _____</p> <p>Were you born in a country other than the US (please circle)? Yes No</p> <p>If YES, where? _____</p> <p>Do/Did you breastfeed (please circle one)? YES NO</p> <p>If YES, for how many months? _____</p> <p>Do you receive WIC (please circle)? YES NO</p> <p>Do you receive SNAP (please circle)? YES NO</p>
--

APPENDIX B

PROJECT BABY BROCHURES, SPANISH AND ENGLISH

Brochure, Spanish



¡Todo bebé merece un buen comienzo!



PROYECTO BEBÉ SPRINGFIELD
C/C Springfield Department of Health & Human Services
93 State Street, Springfield, MA 01103
Teléfono: 413.437.0438 (Se habla español)
Email: projectbaby.springfield@gmail.com
Web: www.facebook.com/safetysleep

¿Qué es Proyecto Bebé?

Proyecto Bebé Springfield se compromete a hacer que la ciudad de Springfield sea una comunidad donde todos estén informados e involucrados en las prácticas diarias para mantener saludables a los bebés, sus madres y sus familias. ¡Aquí en Proyecto Bebé, creemos que todo bebé merece un buen comienzo!

Nuestros Objetivos

- Reducir el número de muertes infantiles en la ciudad de Springfield.
- Educar y crear conciencia en la comunidad (madres, padres, hermanos, tíos, abuelos, y otras personas que cuiden bebés) sobre un embarazo saludable y el modo seguro para que duerman los bebés.
- Asegurar que toda madre, sin importar su raza, etnicidad, edad o situación económica, pueda recibir atención pre-natal y después del parto.
- Colaborar con todas las entidades de salud y sociales para proveer servicios cultural y lingüísticamente competentes.



Información de Contacto

Contactenos si quiere:

- Una sesión informativa gratuita sobre el tema del dormir seguro del bebé presentado por un miembro de Proyecto Bebé.
- Participar en un grupo de la comunidad que da consejos sobre temas de la salud del bebé, la madre y la familia. ¡Su voz es importante – llámenos para participar!
- Formar una colaboración de su organización con Proyecto Bebé.

Recuerde los ABCs del Dormir Seguro

Acueste al bebé
Boca arriba
solo en su **C**una

Nuestros Miembros

PBS es un proyecto del Departamento de Salud y Servicios Humanos de Springfield y su Comisión de Salud Materno-Infantil. Tenemos miembros de las siguientes instituciones, organizaciones, y agencias: Baystate Mason Square Community Health Center, Family Life Center for Maternity Mercy Medical Center, MercyCare Prenatal Centers in Holyoke and Forest Park, MA Department of Public Health, MA Department of Early Education and Care, MA SIDS Center, March of Dimes, Safe Kids of Western Mass, Tapestry Health, Springfield North WIC, Springfield College (Social Work), UMass (Anthropology), Westfield State University (Ethnic & Gender Studies) y agencias de intervenciones tempranas de Springfield.

Projecta Belé
**PROJECT
BABY
SPRINGFIELD**

**Every Baby Deserves a
Great Beginning!**



PROJECT BABY SPRINGFIELD
c/o Springfield Department of Health & Human Services
95 State Street, Springfield, MA 01103
Phone: 413.437.0438 (Se habla español)
Email: projectbaby.springfield@gmail.com
Web: www.facebook.com/springfieldbaby

What is Project Baby?

Project Baby Springfield is committed to making Springfield a community where all are informed and engaged in everyday practices that lead to healthy babies, healthy mothers, and healthy families. At Project Baby, we believe that every baby deserves a great beginning!

Our Goals

- Reduce the number of infant deaths in Springfield.
- Bring education and awareness to mothers, fathers, siblings, grandparents, and caregivers about healthy pregnancies and safe infant sleep.
- Ensure that all mothers, regardless of race, ethnicity, age, or income level, can access excellent pre- and post-natal care.
- Work with all health care and social service entities to provide culturally and linguistically competent services.



Contact Us!

Contact us if you are interested in:

- A **free** informational training session on safe infant sleep presented by a Project Baby team member.
- Becoming a member of our Community Advisory Board. Your voice matters so please contact us to get involved!
- Creating a partnership between Project Baby and your organization.



Our Partners

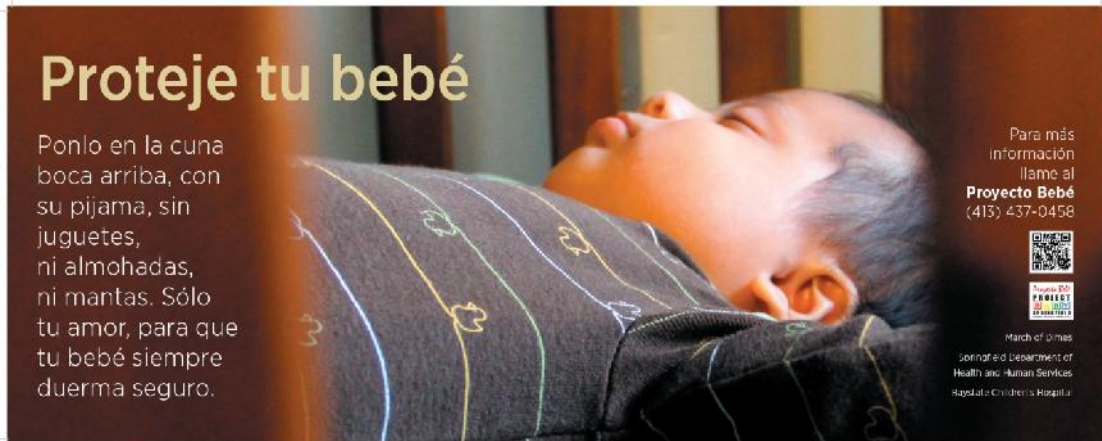
PBS is a part of the Springfield Department of Health and Human Services and its Maternal Child Health Commission. We have members from the following institutions, organizations, and agencies: Baystate Mason Square Community Health Center, Family Life Center for Maternity, Mercy Medical Center, MercyCare Prenatal Centers in Holyoke and Forest Park, MA Department of Public Health, MA Department of Early Education and Care, MA SIDS Center, March of Dimes, Safe Kids of Western Mass, Tapestry Health, Springfield North WIC, Springfield College (Social Work), UMass (Anthropology), Westfield State University (Ethnic & Gender Studies), and Springfield's early intervention agencies.

APPENDIX C

PBS SAFE SLEEP POSTERS, SPANISH AND ENGLISH

Posters displayed on PVTA Buses throughout Springfield.

Spanish Inside Bus –



Spanish Outside Bus –



English Inside Bus –

Protect your baby

Place your baby on his or her back for every sleep. All your baby needs are pajamas. No blankets, pillows, or toys in the crib. Trust your love to be enough. Safe sleep for every sleep.

For more information, call **Project Baby** (413) 437-0458 se habla español



March of Dimes • Springfield Department of Health and Human Services • Baystate Children's Hospital



English Outside Bus –

This is what safe sleep looks like:

Babies sleep safest on their back & in a crib.

For more information, call **Project Baby** (413) 437-0458 se habla español

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