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Preterm Birth And The Perception Of Risk Among African Americans

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**PRETERM BIRTH AND THE PERCEPTION OF RISK
AMONG AFRICAN AMERICANS**

by

GWENDOLYN S. NORMAN

DISSERTATION

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

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MAJOR: ANTHROPOLOGY

Approved by:

Advisor *Date*

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DEDICATION

There are so many important people in my life that I love with all my heart, and to whom I would like to dedicate this work. I have to start with my parents, Henry and Lucille Simpson, who raised me with a strong moral foundation, a joy for life, a love and passion for education, a critical concern for the health and well being of all living things, and the knowledge that learning never ends. My love and respect for them is beyond description.

To my sister, Diane Simpson, who is a role model for me, and my lifelong best friend. Her high and unwavering standards have always encouraged me to do my best, and it is an honor to follow in her footsteps. I could not have completed this monumental task without Diane's keen eye for editing, her strong moral support, and her commitment to hang in there with me, night after night, until the task was completed. There are no bounds to my love and admiration for her, and my debt to her is eternal.

To my beautiful daughters, Latrice and Termina, my niece India, and my grandchildren who have been so understanding when mommy, auntie, or nana, has had to say, "not now." To my husband, Joe L. Norman, who has been my rock through all the ups and downs of this journey, and who has never complained. And finally, to Clifton Eric Banks, my dear cousin and eternal cheerleader, who had far too much personal knowledge of the illness experience. Clifton anxiously awaited this day, but did not live to see it.

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PREFACE

It has been a long journey to get to this point, but it is a good place to be. My career in research began in 1983 when I was hired as the Perinatal Research Nurse Coordinator in the Detroit Medical Center at Wayne State University. It was a rather lonely position at first because I was the only research nurse in the hospital. However, at a major teaching institution that served a large, urban, high risk population, there was an abundance of research that kept me extremely busy.

Many of the studies I was involved with focused on the problem of prematurity, and I was frequently in the position of consenting women who were at risk for preterm delivery. Far too often, when I entered the room of a woman in this condition, I was confronted by someone who was under tremendous stress. The women would share heart-rending stories of complex social issues that were making their confinement to bedrest all but impossible to maintain. Invariably, the women were African American. Without having researched the literature, I was seeing one of the most prominent risk factors for preterm delivery. This experience piqued my interest in health disparities and race.

In the summer of 1990 I had the opportunity to present some research findings at the annual conference of the *International Society on Hypertension in Blacks*. Although the study had shown a statistically significant inverse association between the dietary intake of magnesium and blood pressure readings, the actual impact on hypertension was negligible, and I recognized that my research was not a major breakthrough in the understanding and treatment of hypertension. I was very happy I attended that conference, however, because of what I heard from one of the other presenters. The

presenter mentioned that he was from West Africa, and in addressing the issue of hypertension, he stated that Americans are seriously misdirected in our research efforts if we are considering the people we call “black” in this country a racial group. He said that what we are really studying is a social/cultural group, and not a race of people. He pointed out how many of the serious medical conditions that are prevalent among black Americans are simply not found with any comparable frequency among their counterparts in the areas of Africa that are most likely the land of their ancestry. His comments were particularly intriguing because they supported a developing concern I had.

Because of my undergraduate experience in the school of nursing, I pursued my master’s degree in public health immediately after receiving my BSN in 1974. Although the majority of my undergraduate education dealt with understanding the basic process of disease, and the multiple intervention techniques to effect treatments and cure, I was most excited by my public health rotation. That was because the emphasis in public health was on health behaviors, and primary prevention, as opposed to secondary and tertiary levels of care. I much preferred the idea of preventing disease, to treating it. In order to prevent disease, I would have to know what causes it, and therefore I found epidemiological research interesting. In published epidemiology studies, race, gender and age are the primary demographic host factors cited when identifying a population at risk. These demographics are generally followed by a description of health behaviors that further define the at risk group. The logical sequence in primary prevention is to identify the medical condition, identify the causative factors that lead to the condition, identify those at risk for the condition, and finally identify what the *at risk* group must do

to reduce their susceptibility. Simply stated, in order to reach out to the at risk group, the group must be clearly identified. However, if black race had no biological referent, why was it such a profound risk factor in medical research?

In 1996 I had the opportunity to share in the authorship of a publication of research conducted as part of the Maternal Fetal Medicine Units Network of NICHD. The Preterm Prediction Study enrolled over 2,500 pregnant women across the country and collected numerous biological specimens at various points throughout their pregnancies to identify markers for preterm delivery. One finding, of international importance for the medical community, was the identification of fetal fibronectin as a biomarker for preterm birth. Women in this study, between 25 and 29 weeks gestation, also completed a 28 item Likert scale instrument to assess anxiety, self-esteem, psychosocial stress and depression. The finding from this analysis was that stress was associated with spontaneous preterm birth and low birth weight even after adjusting for maternal demographic and behavioral characteristics (Copper et al. 1996). What our study also found was that “black race” continued to be a significant predictor of preterm birth even after adjusting for all other factors.

This research finding furthered my desire to understand race. In preparation for my dissertation research, I explored the history of race from both the point of view of physical anthropology and cultural anthropology, and the hegemonic relationship in society that places African Americans in a compromised position. This position has profound educational, social, economic and health implications. In order to unpack all of the factors that affect the poor health status of African Americans, each factor needed to be individually assessed. The category of race is a compelling factor, and, though one

often cited in professional research publications, it is very difficult to explain, in light of the origins of the classifications. When anthropologists began discarding wholesale the concept of biological races, there still remained the very statistically significant association between what seemed to be absurd taxonomies, and health risks. Why was this so? If biological races really do not exist, why do these social categories match so closely to health outcomes?

The forensic anthropologist has to provide information from skeletal remains that explain the social reality of the life of the deceased person. This process includes, in no small part, the probable racial categorization. Does this femur have the shaft curvature of an African or a European? What clues do skull vault, nasal aperture, or mandible offer? What is the most likely region of origin? According to David Barondess (February 23, 2001), in data gleaned from the archaeological record from first trimester examinations, the fetus was found to carry important information about the health of the mother. But, is the health of the mother, and the subsequent impact on the developing fetus, only about nutrition, environment, exposure, and activities of daily life, or is there a truly discernible “racial” imprint that also predetermines, to some degree, the outcome of the pregnancy? There was nothing I found in my research that supported that possibility.

I began my search in physical anthropology, but I soon learned that I would not find useful answers in the physical realm. What I learned was that women were being confronted with situations that, to some degree, were beyond their control. How do they justify the unjustifiable, explain the inexplicable? How did the practitioners who cared for these women understand risk?

Although disparities in low birth weight occur on a population level, they are experienced individually by the mother, the infant, the father, siblings and extended family, and by extension, the health care providers caring for the mother and infant. Research on preterm birth has focused on demographics, physiology, nutrition, substance abuse, employment and living environment, all characteristics that can be quantified to provide a view of the social, cultural, and economic factors influencing birth outcomes. The result has been a general portrait of the at risk mother with little attention to the specific, local cultural context of the mother, her family, and the health practitioners who care for her. I wanted to understand how people in these different positions and relationships to the birth mother understood the risks the mother and infant faced. I further wanted to examine if they blamed the mother or assigned responsibility for the birth outcome to her, and to what extent the mother shared their understandings of risk or how they differed. In this way I hoped to move beyond attention to the mother as the sole unit of analysis, whose behavior is presented as the result of rational calculations, and instead move to the nature of her personal and intimate experience and understanding of the risks she faced. In this pursuit, I also included in my focus attention to the views of the health care professionals and to the mother's family (her mother and the infant's father) in order to understand the logic by which they assigned responsibility to the mothers. I sought to understand the areas where mothers, and those who cared for and about them, coincided in their understanding of risk and responsibility and how these views diverged.

This work, therefore, explores the different configurations of these beliefs among African American women hospitalized to prevent a preterm birth, the fathers of their

unborn children, the mothers of the pregnant women, and the health practitioners who care for them. It will identify and describe the nature and sources of these beliefs, the values and meanings associated with them, the logic/rationale for assigning responsibility for the pregnancy outcomes held by these different cultural actors, as well as the explanatory models that each positioned actor group holds.

TABLE OF CONTENTS

Dedication	ii
Acknowledgments	iii
Preface	v
List of Tables	xiv
Chapter 1 Introduction	1
<i>Preterm Birth: The Factors that Determine Risk</i>	5
<i>Race and Risk</i>	29
<i>Biological Anthropology and Race</i>	47
<i>Race and Health Disparities Research</i>	49
<i>Medical Anthropology and Race</i>	54
Chapter 2 Stress, Racism and African American Women's Health	59
<i>Stress</i>	63
<i>Stress in Pregnancy</i>	66
Chapter 3 Risk Theory, Risk Perception and Preterm Birth	77
<i>Risk Theory</i>	77
<i>Epistemological Positions on Risk</i>	78
<i>Risk Society</i>	80
<i>The Cultural Theory of Risk</i>	81
<i>Risk Perception</i>	86
<i>Risk Perception and Preterm Birth</i>	90
Chapter 4 Cross Cultural Perspectives on Risk	97
Chapter 5 Methodology	102

<i>Research Questions</i>	102
<i>Enrollment Criteria</i>	103
<i>Rationale for Study Design</i>	103
<i>Procedures</i>	105
<i>Data Collection</i>	105
<i>Data Analysis</i>	107
<i>Notes from the Field</i>	108
Chapter 6 The Ethnographic Setting- Detroit, Michigan	114
<i>A Historical Perspective</i>	116
<i>Health of Women and Children in Detroit</i>	125
Chapter 7 Case Study 1-Risk is Explained by Maternal Behaviors	130
Chapter 8 Case Study 2-Risk is Explained by Maternal Stress	149
Chapter 9 Case Study 3-Risk is Unexplained	164
Chapter 10 Explanatory Models of Providers	182
Chapter 11 Discussion	224
Chapter 12 Conclusion.....	248
Appendix A- Patient Consent Form	263
Appendix B- Family Member Consent Form	269
Appendix C- Provider Consent Form.....	272
Appendix D-Edinburgh Depression Scale	275
Appendix E- Code Frequencies	278
Appendix F- Kessner Index; Infant Statistics Definitions	279
Appendix G- Original 2009 Institutional Review Board Approval	280

Appendix H- Current 2012 Institutional Review Board Approval	281
References.....	282
Abstract.....	329
Autobiographical Statement	331

LIST OF TABLES

Table 1: Profile of Mothers and Children in Wayne County and Detroit in 2009	126
Table 2: Births by Prenatal Care by Race and Ancestry of the Mother Wayne County Michigan Residents, 2009.....	127
Table 3: Births by Prenatal Care by Race and Ancestry of the Mother Detroit, Michigan Residents 2009.....	127

CHAPTER 1

INTRODUCTION

African American women suffer disproportionately from the experience of premature deliveries. The burden of this disparity in pregnancy outcomes is felt not only by the mother, her family and her health care providers, but by the greater society as well. Identifying African American women as being *high risk* remains a common practice in the biomedical field, but determining how women and their families perceive this designation has not been explored. The question of how this risk is perceived, including its meaning, interpretation and significance, suggests the need for anthropological inquiry.

African Americans are affected by a two- to threefold increase in the incidence of low birth weight and preterm infants when compared to their white counterparts (Lu and Halfon 2003). As a public health concern, preterm delivery has considerable medical, financial and psychosocial implications (Behrman and Butler 2007). Equally important is the impact preterm birth has on the rate of infant mortality. The primary cause of infant mortality is preterm birth, and the disproportionate rate of infant mortality among African Americans is the reason the United States has dropped in rank globally to a position of 29th for infant mortality. In 1960 the United States was ranked 12th among 37 industrialized nations, but as of 2004, the last year for which the CDC has complete international data, the United States had fallen to the 29th position (Murphy et al. 2012; Martin et al. 2009).

In biomedical research, clinical risk factors for preterm labor and preterm delivery have been extensively enumerated, identifying “race,” socioeconomic status, health

behaviors, prenatal care, health history, and certain physical findings as the key factors contributing to the explanation of the disparity.

In medical anthropology, qualitative research studies regarding reproduction frequently address such topics as fetal surveillance; the medicalization of childbirth; new and assisted reproductive technologies (ART); the ambiguities related to the beginning and ending of life; abortion; the reification of the fetus; and the social establishment of personhood. However, perception of risk and its cultural construction in pregnancy and childbirth has not been a research focus. While much has been written on risk assessment from the expert clinical perspective on prematurity, there is little data on the lay perspective of risk and what impact these perspectives have on women and families experiencing premature deliveries. In fact, in the case of low birth weight, the focus of study has been almost exclusively at the group level, reflecting the quantification approach of epidemiology and the search for predictive patterns to explain the problem; little attention has been paid to the mother or to those who care for and about her.

The focus of this research is to determine just how the rational clinical discourse concerning risk assessment through probability and statistics is embodied, interpreted and expressed in the individual woman at risk, and how women understand and identify with this discourse. This research explores how the culturally informed construction of risk is understood and interpreted by the family experiencing prematurity—the pregnant mother, the father, and the mother’s mother. It also examines how the mother may perceive herself as a risk to her fetus.

“The designation of the label ‘at risk’ often serves to reinforce the marginalized or powerless status of individuals, which places them in a network of surveillance, monitoring and intervention” (Lupton, 1999b). Many African American women who are at risk for preterm delivery find themselves in this position described by Deborah Lupton. It is especially true for those who have already experienced a preterm birth. In contemporary society, where the individual is held responsible for reducing the risks of misfortune, the concept that the mother must in some way be responsible for preventing prematurity can lead to anxiety, and a sense of loss of bodily control (Williams and Mackey 1999). Issues of causality arise with questions such as, who is at fault, what has happened and why it is happening. This individualization of risk, typical of the neo-liberal approach to health care and health policy, emphasizes the responsibility of the individual and directs attention away from the group and larger cultural context in which these births occur (Rose 1993).

An appreciation of the mother’s and family’s interpretation of risk and responsibility will provide insight into both the mother’s experience and the meanings she and her family bring to the pregnancy. Knowledge of how mothers and families interpret risk and responsibility serves to advance our understanding of how culture structures the nature and meaning of risk and how these meanings influence health behavior at a particularly vulnerable time for the *at risk* mother. This research frames, from the point of view of the patient, what it means to be both at risk and to be a source of risk.

Additionally, physicians, nurses and medical assistants enhance this discussion, and help to identify differing locations of risk. There are multiple meanings for

prematurity and preterm delivery that go beyond the culturally available knowledge shared by the pregnant women. These meanings can be obtained utilizing informants that include not only pregnant patients, but also the fathers of their babies, the patients' mothers, and the doctors, nurses and medical assistants who care for them. Locally derived meanings offer a piece which has not yet been elucidated.

The culturally informed construction of risk meanings for the African American family and the African American provider, and not just the reflexive response to expert knowledge, offers insight into alternate knowledge systems and how those knowledge systems impact health behaviors and the health care experience. The study examines the interaction of multiple conceptualizations and constructions of risk and explores the sources of similarity and difference in the location of risk, assigning responsibility for managing the risk, and control over of the outcome.

The problem of preterm birth has profound national and international implications, but is one that is experienced on a very personal and individualized level. This individual experience is culturally constructed. Yet the elicitation of the narratives of women at risk and the elucidation of their explanatory models has not occurred. Nor have the explanatory models of individual family members or health care providers been elicited. Employing Arthur Kleinman's patient model theory, and Linda Hunt's theoretical framework, this study focuses on the use of an expanded explanatory model design as a heuristic for discovering the complexities of risk perception.

Anthropological theory will be enhanced with the data emerging from this study regarding the social and cultural norms that impact risk assessment and the behaviors related to protection from risk. Anthropologists have explored, in numerous cross-

cultural settings, the culturally perceived vulnerability of a pregnant woman, and the understanding she shares with other family members about her responsibilities for ensuring a safe childbirth. These understandings are in some ways analogous to the western concept of risk, in that they specify how and in what ways, in this case, the mother and her fetus may be vulnerable to a negative birth outcome. These understandings, while not biomedically informed, are clear about the distribution of responsibility for a normative outcome as well as the sources of threat to that outcome.

These understandings reflect deep seated structures, beliefs, practices, and meanings in a culture. Mary Douglas, writing about risk, has described the relationship between these understandings and the indigenous culture in which they are located. The work of Mary Douglas will guide the basic anthropological analysis of the cultural construction of the risk. Other key theorists such as Lupton and Foucault will extend the analysis grounded in the theory of Douglas. This theoretical advancement will occur through the study of how risk is culturally constructed in African American families experiencing premature births and how it is constructed by the providers who care for them.

Preterm Birth: Factors that Determine Risk

Preterm birth profoundly challenges our nation. According to a recent publication by the National Institutes of Health, “the overall high rate of preterm birth in the United States and the persistent racial-ethnic gap is one of the most significant health problems today” (Behrman and Butler 2007). This publication, *Preterm Birth: Causes, Consequences and Prevention*, is a comprehensive review of the current state of research and findings regarding prematurity and low birth weight infants, and offers

clear insight to the fact that preterm birth is the final common pathway from multiple etiologies (Varner and Esplin 2005). While the rate of survival of preterm infants has improved dramatically through remarkable strides in perinatal treatment, medical technologies, and neonatal care, there has not been commensurate success in understanding and preventing preterm birth. The following discussion will cover the numerous, and often overlapping, factors that influence prematurity, the consequences of preterm birth, and what is known and unknown about why African American families are so adversely affected.

International Standing

Although the actual ranking of the United States in comparison to other developed countries is contested, primarily due to the use of non-standardized criteria for assessing preterm birth across nations, this country, nonetheless, does not fare well. There has been a steady rise in the percentage of preterm births over the past two decades, and perhaps the most serious consequence of these preterm births is infant death. The Infant Mortality Rate (IMR) is calculated as the number of deaths of infants under one year of age per 1,000 live births and is considered to be one of the most important indicators of a nation's health. The reason why it is so important is that the IMR is associated with numerous other health factors, such as quality and access to health care, public health practices, socioeconomic conditions and maternal health (MacDorman and Matthews 2008). In 2010 the overall IMR for the United States was 6.14, ranking this country as 29th for IMR among industrialized nations. The IMR for African American infants was 11.61 in 2010, more than double the rate for white infants, which was 5.19 (Murphy et al. 2012). In 1998 (White House Fact Sheet 1998), the

Healthy People 2010 government initiative set a national goal to reduce the infant mortality rate to 4.5 during the decade from 2000 to 2010 . Unfortunately, not only was this goal not realized, but the Healthy People 2020 goal has upwardly revised the IMR goal to 6.0. This lack of progress in reducing the infant mortality rate is a direct reflection of the failure to significantly narrow the ethnic disparity in birth outcomes.

Long-term Consequences of Preterm Birth

Preterm birth is defined as birth prior to 37 completed weeks of gestation and very preterm births are those that occur at less than 32 weeks. In 2009, in the United States, preterm births comprised 12.2 percent of all births; however, 17.5 percent of African American infants were born preterm, compared to 10.9 percent for whites. African Americans were most likely to be born very preterm, 3.9 percent, while only 1.6 percent of white infants were in that category (Martin et al. 2011). This disparity in the very preterm birth rate greatly impacts the IMR, because these are the infants most likely to die. Death however, is only one consequence of preterm birth. Children born preterm can be faced with serious challenges throughout their lives. These children are disproportionately affected with cognitive deficits, which impact their mastery of language and performance on intelligence tests, and they are also less likely to graduate from high school (Giscombé and Lobel 2005). Also, a woman whose own birth weight was low, is more likely to deliver children who are low birth weight, and these infants have higher risk of dying as newborns (Skaerven et al. 1997). Giscombé and Lobel reference the work by Barker (2000) on fetal origins of adult disease by explaining that “cardiovascular disease, hypertension, and NIDDM are programmed in utero because the physiological adaptations, such as changes in blood circulation,

vascular structure, insulin resistance, and liver function, all of which promote survival in an undernourished fetus, persist in adulthood” (Giscombé and Lobel 2005: 664).

Societal Costs

There is a staggering economic burden associated with the many costs of preterm birth, estimated at a minimum of \$26.2 billion in 2005; the cost was \$51,600 for each preterm infant. This estimated annual amount represents \$16.9 billion in medical care services, and \$1.9 billion for maternal delivery costs. Longer term, the special education costs for early intervention services total \$611 million. These expenditures, however, do not include costs for the four most disabling conditions of preterm infants: cerebral palsy, mental impairment, vision impairment, and hearing loss. The special education needs of these children are estimated at \$1.1 billion per year (\$2,200 per preterm infant), and the lost household and market productivity resulting from these lifelong conditions add another \$5.7 billion (\$11,000 per preterm infant) in costs (Behrman and Butler 2007). Other than lifetime care for the four major disabling conditions, most of the cost estimates are based on early medical care during infancy, primarily during the initial hospitalization. What is lacking is a better assessment of the long-term caretaker costs, and the outpatient, non-infancy care (Zupancic 2006).

Socioeconomic Status

There are numerous maternal factors that have been associated with preterm birth, the most common of which is socioeconomic status (SES). The conventional explanation has been that race serves as a proxy for economic status, and that the lower income, educational attainment, and occupational status of African Americans are the reasons for the disparities in birth outcomes between blacks and whites in the

United States. However, in studies that have controlled for socioeconomic status, there still remains an unexplained gap. “High socioeconomic status does not provide the same level of protection for African American women as it does for white women” (Lu and Halfon 2003:20). One issue is the difference between income and wealth. Giscombé and Lobel (2005:667) note from the Panel Study on Income Dynamics that approximately 70 percent of household wealth is passed down from one generation to the next, and African American families have, “just nine cents for every dollar of wealth accumulated by European American families” (University of Michigan 2000). So, while middle-class African Americans families may have incomes similar to white families, they have only a third of the wealth, or net worth (Lu and Halfon 2003:20). Similar to income, educational attainment also does not confer equal protection.

From 1998 to 2000 educational attainment data was compared with birth outcomes. For women with less than 8 years of schooling, 19.6 percent of the African American children were born preterm, compared to 11.0 percent for whites. At the highest level of education in that review, those with education greater than or equal to 16 years, the percent of preterm births for African Americans was 12.8, while it was 7.0 for whites (Behrman and Butler 2007). What is most notable in these two extremes of education is that African American women with a four-year college degree still had a rate of preterm birth higher than white women with less than an 8th grade education.

In a study by Alexander et al. (1999) women considered to be at low risk were compared by ethnicity. These were women between the ages of 20 and 34, who completed at least 13 years of education, had at least one successful pregnancy, and, along with other medical low risk factors, had no history of alcohol or tobacco use during

pregnancy. What was found was that African American women had a 2.64 times greater risk for having a low birth weight infant, and 1.61 times greater risk for infant mortality when compared to their white counterparts. Along with the data described above, some of the most compelling data to suggest that SES is not a factor in the disparity in birth outcomes is the finding that the disparity in outcomes increases between whites and blacks as education increases. One large study (Din-Dzietham and Hertz-Picciotto 1998) found that there was a 20 percent decrease in infant mortality for white women with education beyond high school, but the same did not hold true for African American women. In another study demonstrating that education was not as protective for black mothers as it was for whites, African American women with a college education were 2.48 times more likely to deliver a low birth weight infant, and 1.67 times more likely to deliver preterm (McGrady et al. 1992).

Anecdotal evidence of this fact was discussed in a published interview with Dr. Sophie Womack, an African American neonatologist from Detroit (Kashef 2003). She explained she was surprised that both of her daughters, born two years apart, were each preterm. She was well educated, healthy and had good nutrition, good medical care and a good income. The only factor that put her at risk was that she was a black woman. Noting that research has debunked the notion that socioeconomic status and related factors are the source of the problem, the article quotes Dr. Michael Lu, who said that looking at prenatal care utilization and maternal behaviors was not the answer. "What we're finding is that these differences really explain very little of the disparities in birth outcomes" (Kashef 2003). Dr. Lu proposes a life course approach, that will be discussed later, that encompasses a long-term perspective on prematurity rather than

simply examining risk factors during pregnancy. Dr. Womack acknowledged the high level of ongoing stress related to discrimination that she and fellow black physicians encountered in their careers, despite their education and income, and said, “those things do factor into what happens in our pregnancies” (Kashef 2003).

Prenatal Care

An assumption could be made that African American women who seek early and consistent prenatal care would diminish their risk of delivering preterm, but Shinono et al. (1986) found African American women who initiated prenatal care in the first trimester still had a two-fold increase in low birth weight infants, even when the analysis controlled for smoking and alcohol use (Giscombé and Lobel 2005). In a more recent study, Healy et al. (2006) reviewed 35,529 pregnancies from 1999 to 2002 where the women initiated prenatal care in the first trimester, and analyzed pregnancy outcomes by ethnicity. When compared to whites as the referent, the odds ratio for blacks was 4.4 for fetal demise at less than 24 weeks gestation, 3.5 for fetal demise at greater than or equal to 24 weeks gestation, 6.3 for neonatal demise, and 4.3 for overall perinatal mortality including the three previous categories (Healy et al. 2006:628). The authors concluded that early access to prenatal care to minimize ethnic disparities in perinatal mortality was not a sufficient solution. Additionally, equal utilization does not mean equal care. Studies have shown that during the prenatal period of care, African American women were less likely to be offered information, given certain exams, blood tests, ultrasound exams, or be given the treatments offered white women (Lu and Halfon 2003).

Maternal Age

Women at either end of the reproductive age spectrum are at greater risk for delivering preterm. Both young teenagers and women over age 35 are more likely to deliver prematurely. For very young women, though not clearly understood, this may be attributable to their biological immaturity, their generally poor socioeconomic circumstances, or some combination of both (Fraser 1995; Akibami 2000). For older women, the reasons for increased risks, in general, are not known (Behrman and Butler 2007). However, Geronimus, who studied urban African American women, attributes their increased risk to the concept of *weathering*, “whereby a women’s health reflects the cumulative impact of her experiences from conception to her current age” (Geronimus 2001:135). Geronimus described this as the long-term physiological manifestations of social inequalities and gives teen pregnancy as an example. The oddity is that for whites, teen mothers have the worst birth outcomes of any white group, but their rate of preterm birth is still lower than the preterm birth rate of African American women in their twenties and early thirties, including successful, economically advantaged black women. However, black teens in low-income communities have fewer preterm births than African American women in the 20-30 age group (Geronimus 2001). These facts support the theory that as African American women age they suffer from successive and progressive environmental and social insults to their health that begin very early in life. The weathering concept will be further addressed in the discussion regarding stress and pregnancy.

Marital Status

Regardless of ethnic group, unmarried women are more likely to deliver preterm than married women (Martin et al. 2011). However, marriage is not equally protective across all groups. Women over 35 years of age, and African American women, derive the greatest improvement in birth outcome when they are married (Behrman and Butler 2007). Though not clearly understood why marriage is protective, the higher rates of preterm birth among unmarried women are generally attributed to a lack of social support and resources (Waldron, et al. 1996). Nationwide 41 percent of births were to unmarried women in 2009, for black mothers 72.8 percent were unmarried, and for white mothers, 29 percent were unmarried (Martin et al. 2011).

Maternal Behaviors

In general, favorable lifestyles are associated with favorable pregnancy outcomes (Behrman and Butler 2007). However, there is not compelling evidence that less favorable behaviors are strongly associated with preterm birth, and the contribution of behavioral risk factors to disparities in birth outcomes appear to be quite modest (Lu and Halfon 2003).

Tobacco and Alcohol

Studies have found that African American women are less likely to smoke during pregnancy than white women (Beck et al. 1999), but those black women who did not smoke during pregnancy still had higher infant mortality rates than white women who did smoke (Matthews and MacDorman 1999). Tobacco use, though consistently implicated in placental abruption, infant mortality, and a reduction in weight at birth (Cnattingius 2004), is not clearly a factor in prematurity. In fact, research has found

conflicting results from no effect at all (Goldenberg et al. 1998) to a significant association (Nordentoft et al. 1996). There are also contested results regarding whether there are differential effects on prematurity based on the race/ethnicity of the smoker (McDonald et al. 1992).

As with smoking, alcohol consumption has well documented effects on the developing fetus, and long term consequences for the child exposed to alcohol in the womb (Sokol et al. 2003). Women who are moderate drinkers (Savitz and Pastore 1999) and heavy drinkers (Parazzini 2003) during pregnancy also have an increased risk of delivering preterm.

Illegal Drug Use

Cocaine use during pregnancy has been studied extensively, with a documented increase found in preterm birth when compared to non-users (Holzman and Paneth 1994). However, the lifestyle of women who are chronic cocaine abusers during pregnancy introduces confounders that may diminish the contribution of cocaine, despite the biological plausibility of cocaine as a pathway to preterm birth. Cocaine use is also associated with placental abruption, early miscarriage, fetal stroke, low birth weight, learning and behavioral disorders, and some birth defects (Bauer 2005; Viadef 2003; Cocaine 2005). Heroin, like cocaine use during pregnancy, can lead to placental abruption, poor fetal growth, premature rupture of membranes, and preterm birth. Marijuana, however, one of the most commonly abused drugs among young pregnant women, has not been shown to increase the risk for preterm birth (National Survey on Drug Use and Health 2007). The use of other drugs, such as Ecstasy, methamphetamines, and amphetamines, has been associated with intrauterine growth

restriction, and fetal anomalies, but is not strongly associated with prematurity (Smith 2006).

While the prevalence of smoking, drinking alcohol and the use of drugs during pregnancy is no greater among blacks than whites, disparities in birth outcomes for users of these substances continue to negatively impact black families (Singh and Yu 1995).

Sexual Activity

Sexual activity, specifically intercourse, has long been suspected as a precipitator of preterm contractions and labor. The concern has been the direct effect of semen, and changes to the vaginal microflora, but several studies in the 1980s confirmed that sexual activity did not lead to preterm birth (Behrman and Butler 2007). Quite in contrast, one recent study found that sexual activity was actually associated with a decreased risk of preterm birth (Sayle et al. 2003). This finding, however, may be explained, in part, because women with certain high risk factors that contraindicate sexual activity will abstain for a period of time during pregnancy.

Employment, Work, and Physical Activity

In general, women are encouraged to exercise and maintain physical activity during pregnancy. In fact, Sternfeld (1997) found that physical activity likely offers a protective effect against preterm birth. While the physical demands of a strenuous job have been implicated in the onset of preterm labor and preterm birth, data is very inconsistent on this point. Women who are employed tend to be healthier than women who are unemployed, most likely as a result of increased economic status, health care coverage, and, in many cases, job satisfaction. Employed women are far less likely to

deliver preterm than women who are unemployed (Savitz and Pastor 1999). However when a job becomes a source of psychological stress, where there is a low level of job satisfaction, where the working conditions are adverse, and the work is very physically demanding, the association to preterm birth is more pronounced (Saurel-Cubizolles et al. 2004; Mamelle et al. 1984; Saurel-Cubizolles 1991).

In a study of the association between job strain and birth outcomes (Oths et al. 2001), women who were scored as having job strain based on psychosocial and physical demands were more likely to have low birth weight babies. While black women who felt discriminated against at work were three times more likely to experience job strain (Oths et al. 2001:756), even those black women who reported no strain still had a disparity in birth outcomes. Hickey et al. (1995) found no relationship between work characteristics and preterm delivery among low income black and white women except that there was a significant reduction in preterm delivery among black women who were allowed to take unscheduled rest breaks at work (Hickey et al. 1995: 416). Finally, Brett et al. (1997) in studying occupational stress among women in North Carolina did find an association between high strain work and preterm delivery. In their examination of ethnicity they concluded, "job stain was somewhat more consistently associated with preterm delivery among black women, supporting the hypothesis that black women may be at higher risk for this pregnancy outcome partially as a result of their increased exposure and response to stress" (Brett et al 1997:202).

Social Support

Social support can encompass the provision of emotional concern, instrumental aid, and information (Behrman and Butler 2007). In general, studies of support have not

shown compelling evidence that it reduces preterm birth, perhaps due to the varying definitions and manners of assessing support in this body of research. However numerous observational studies have shown a significant association between social support and birth weight (Buka et al. 2003). Additionally, intervention studies that offered various types of support did not show a decrease in preterm birth, and the results of randomized trials of social support have been inconsistent (Pickett et al. 2004). The conclusion by Goldenberg and Rouse was that “there is little evidence to support the belief that a significant reduction in preterm birth can be achieved through the systematic provision psychosocial support” (Goldenberg and Rouse 1999:114). This finding may in part be because the quality and quantity of the supportive intervention could not adequately address the support needs of the target population, or that the support did not mimic a natural social network. However, Mullings and Wali (2001) found in ethnographic studies that women may not always perceive their own natural social networks to be supportive.

As of yet, the manner in which social support can impact preterm labor has not been identified and specific sources of effective support may differ by ethnic group (Behrman and Butler 2007). For many African American women, the partner makes the biggest difference. Lu and Chen (2004) identified that partner support was associated with longer gestations, and improved fetal growth. Conversely, they also noted that partner-associated stress was 163 percent more likely to be experienced by African American women during pregnancy than by white women (Lu and Chen 2004:696). “Epidemiological evidence is strongest for a protective role from an intimate partner,

rather than from other sources, and for emotional rather than instrumental support” (Hoffman and Hatch 1996).

Living Environment

The environment in which a woman lives can impact her vulnerability and resistance to health risk factors (O’Campo et al. 1997). In the study by O’Campo et al. (1997) in Baltimore, while controlling for other individual level risk factors, the authors found a relationship between “high-risk” neighborhoods and the incidence of low birth weight infants born to the women who reside there. Neighborhoods were rated high-risk or low-risk based on the ratio of homeowners to renters, unemployment rate, rate of housing violations, per capita crime rate, average wealth, and per capita income. O’Campo et al. (1997) also noted that while early prenatal care initiation had been shown to be protective for some women, that protection was lost regardless of the gestational age when prenatal care began, if the woman lived in a high risk neighborhood (O’Campo et al. 1997).

Utilizing 2000 Census data, an analysis of 1,944,703 births was conducted for 237 metropolitan areas (Osypuk and Acevedo-Garcia 2008); Detroit, Michigan was one of the cities included in this analysis. Based on five segregation measures, if a community scored as highly segregated on four or five of those measures, the community was characterized as hypersegregated. The study found that there was a significantly higher rate of preterm birth among blacks in hypersegregated areas versus blacks in non-hypersegregated areas. Additionally, the higher the age of the mother in the hypersegregated area, the greater the likelihood she would deliver preterm. The probability of preterm birth was higher and the ethnic disparity in outcomes greater for

blacks living in hypersegregated metropolitan areas. The graph of these results showed that the slope of association between preterm birth and age was not only steeper among black women than among white women, but the graph also illustrated a steeper slope for black women in hypersegregated areas than for black women in non-hypersegregated areas. “This finding suggests that age related preterm birth patterns may be related to stressors associated with residential hypersegregation facing black women” (Osypuk and Acevedo-Garcia 2008:6).

The impact on prematurity and low birth weight can be related to the inequalities that characterize hypersegregated black neighborhoods: high poverty, high crime, lack of access to nutritious food, and adverse health products. In one study, white neighborhoods were found to have four times as many supermarkets as black neighborhoods, while in the black neighborhoods there were triple the number of locations for alcohol consumption (Morland et al. 2002). Women may experience increased stress through the constant triggering of the “fight or flight” response to living in violent crime areas, which can exert wear and tear on the body. In support of this concept, Korte (2000) found that (1) racial discrimination, (2) perceived stress, and (3) neighborhood crime were predictors of gestational age at delivery in African American women.

Osypuk and Acevedo-Garcia (2008) called for a greater investigation into the metropolitan context of racial inequality after noting in their study that segregation was only one indicator of the impact of institutional racism on blacks, and that the effect of segregation on birth outcomes was small in comparison to the impact of ethnicity on the disparity in outcomes. Their conclusion was that “the public health significance of the

small effect of segregation resides in pursuing social context as a cause of preterm birth, which suggests new avenues for preventive strategies, by addressing broader determinants than those specified within a narrow biomedical approach” (Osypuk and Acevedo-Garcia 2008:8).

Reagan and Salsberry (2004) documented the negative impact of “neighborhood disadvantage” on poor birth outcomes for black women. They supported the theory that the resultant psychosocial stress of living in these disadvantaged neighborhoods influenced preterm birth through “neuroendocrine and immune pathways that affect susceptibility in infection and hypertension” (Reagan and Salsberry 2004:2218). Exposure to income inequality was a particular stressor noted in that article. Also, Culhane, et al. (2001; 2002) found that high levels of chronic stress are associated with bacterial vaginosis in pregnancy and can explain the higher rates of the condition in African American women living in poorer or less advantaged neighborhoods than whites. Reagan and Salsberry contrasted neighborhood disadvantage with the “social capital” that comes from living in an advantaged neighborhood where there are better channels of communication, superior community resources, social support and positive social norms that promote healthy behaviors (Reagan and Salsberry 2004). This social capital offers theoretical protection against the high risk of prematurity for African American women.

In a more nuanced study of how residence can impact birth outcomes, Pickett et al. (2005) sought to determine the effect of income incongruity and racial density on African American women living in Chicago. While adverse neighborhood conditions were related to poorer pregnancy outcomes, black women who lived in better areas in

which they were a minority did not experience the added protection against preterm birth. It was only when the better neighborhood was primarily African American, and the socioeconomic status of the childbearing woman demonstrated positive income incongruity—or residence in a wealthier census tract than might be expected—that a pregnancy benefit is obtained. As Dressler and Bindon (2000) found, when individuals are able to meet or exceed the social and economic expectations of their cultural group then there is the positive health impact of “cultural consonance.” The finding that African American women fare better when they constitute the majority in their neighborhood suggests that, “the social networks of African American women in a racist society may be strongest when they resided in areas where they are not a racial minority. Exposure to structural and interpersonal racism is a deep rooted source of acute and chronic stress for African Americans” (Pickett et al. 2005:2230). The positive income incongruity was only associated with better birth outcomes when African American women lived in communities that were over 90 percent African American. While positive income incongruity is beneficial to white women there is no benefit for African American women when they are the minority. The suggestion is that the material benefits are outweighed by the psychosocial disadvantage of being exposed to stigmatization, imputations of inferiority and the loss of social support (Pickett et al. 2005:2235). The chronic stress that can develop from constant exposure to prejudicial treatment from living as a minority in an advantaged neighborhood evinces a pathway through which social context can impact pregnancy outcomes (Pickett et al, 2005).

Three years after the publication of the study by Pickett et al., a group of researchers in North Carolina used those research findings as a basis to further

investigate how positive income incongruity in Durham and Wake counties might influence birth outcomes (Vinikoor et al. 2008). Not only did their research confirm the finding of Pickett et al., but by studying communities less segregated than those found in Chicago they showed that positive income incongruity remained protective for African Americans living in high relative density tracts as low as 75 percent. Again, the positive income incongruity offered no protection in communities with a low relative density of African Americans.

Adverse neighborhood conditions can affect women through the social environment, the service environment, and the physical environment. All three of these dimensions are linked to socioeconomic disadvantage and are implicated in the high rate of preterm birth among African American families (Behrman and Butler 2007).

Infection

Bacterial vaginosis (BV) is the most common genital tract infection among childbearing age women (McGregor and French 2000) and has consistently been associated with a two-fold increase in the risk of preterm birth (Andrews et al. 1995, Goldenberg et al. 1996, Hillier et al., Meis et al 1995). While recent large studies have failed to demonstrate any benefit of eradication of BV in the prevention of preterm birth, there is evidence that among BV colonized women there are subgroups that have biologic differences making some disproportionately susceptible. These differences include mechanical, biochemical, and environmental disadvantages. It is likely that including “lower risk” BV positive women in these previous treatment trials may have obfuscated the potential benefits of a more targeted therapeutic approach. However, antibiotic treatment alone may not be the answer.

Research has shown there to be higher vaginal hydrolytic enzyme levels in women delivering preterm compared to those who deliver at term. A possible explanation is that these microbial and host factors actually modulate individual susceptibility to the altered vaginal flora and hence to preterm birth among BV positive pregnant women. Additionally, it seems that it is twice as common for African American women to harbor this “aggressive BV” environment. Although there is evidence that social conditions can moderate the effect of this toxic exposure, there is not, as of yet, clear data on how chronic stressful conditions may moderate the pathogenesis of BV or alter the cervico/vaginal immune environment and lead to preterm birth (Bellinger 2000).

Genetics

This predisposition to infection may also be related to genetics. African American women have higher frequencies of pro-inflammatory cytokine gene polymorphisms and other polymorphisms that may increase their risk for preterm labor (Varner 2005). However, there are several other reasons why preterm birth may have a genetic basis.

First, women at the greatest risk for delivering preterm are those who had a preterm delivery in a prior pregnancy (Porter 2001). The second reason is that there are a small number of single gene disorders in women that are frequently associated with a predisposition to delivery preterm. The third factor, as discussed previously, is that black women have a rate of premature delivery that is twice that of whites, even when controlling for social and economic factors. Wang et al. (1995), noting that there is a familial tendency toward delivering low birth weight infants, have postulated that both the intergenerational and intragenerational effects of low birth weight are mediated

through attenuated growth of the fetus, and through impaired ability to sustain a pregnancy to term. However, the specific biologic mechanisms that are responsible for these effects remain unknown. Until recently, there were virtually no studies of genetic factors in preterm birth. In part, the reason for this was that infant mortality was so high among preterm infants that they did not survive long enough to pass on the genetic tendency. With the substantial advances in the care of premature infants over the past few decades, women who were born extremely premature are now having babies.

If genetics plays a substantial role, as may be suggested by research data, there should be a traceable ancestral link. One study was designed to identify such a link. To explore the question of whether there is a historical genetic link, Dr. Richard David and Dr. James Collins published a study in 1997 in the *New England Journal of Medicine* entitled "Differing Birth Weight Among Infants of U.S. Born Blacks, African-Born Blacks, and U.S. Born Whites." Vital records for 1980 through 1995, from the Illinois Department of Public Health were reviewed to determine the distribution of birth weights of infants born to three groups of women: U.S. born blacks (UBB), African born blacks (ABB) and U.S. born whites (UBW). Each record was coded for mother's race, mother's place of birth, and mother place of origin or descent.

Data on infants of 3,134 ABB, and a random sampling on infants of 43,322 UBB (7.5 percent of the total) and 44,046 UBW (2.5 percent of the total) were analyzed. The mean birth weight for the UBW was 3,446 grams, the mean birth weight for the ABB was 3,333 grams and the mean birth weight for the UBB was 3,089 grams. The difference was statistically significant. The incidence of low birth weight was 13.2

percent among infants of UBB, and 7.1 among ABB, as compared with 4.3 among UBW (relative risks of 3.1 and 1.6 respectively).

Among the women at lowest risk (those 20-39 years old with 12 years of education for themselves and their spouses, early prenatal care, pregnant for the second or third time, and no previous fetal loss) the rate of low birth weight in infants of ABB was 3.6 percent, and was closer to the rate of infants of white women, 2.4 percent. The rate of low birth weight in infants of UBB women remained high, at 7.1 percent.

In most studies, racial differences in birth weight persist independent of numerous social and economic risk factors, leading some researchers to suggest a genetic basis for the difference. This study did not support that theory. Genetically, African Americans are considered to have a 20-30 percent European admixture that has occurred since the 17th century. If genetics played a prominent part in determining black-white differences, infants of ABB would be smaller than those of UBB. Just the opposite was true. Infants of ABB were significantly larger. Additionally, when controlling for the outcome of prior pregnancy, the rate of very low birth weight among infants of ABB was almost identical to that of whites.

However, there is emerging research evidence of a genetic cause prompted by investigations into the ongoing finding of familial aggregation and racial disparities in prelabor premature rupture of membranes (pPROM) and preterm birth (Romero et al. 2010). While pPROM complicates approximately 3-4.5 percent of all pregnancies in the United States, it is responsible for nearly 30 percent of all preterm births (Romero et al. 2010).

A recent publication by Romero et al. (2010) identified DNA variants in a maternal gene that doubled the risk of pPROM. This study supported the hypothesis that these genetic variations, which may be involved in the weakening and rupture of membranes, predisposed women to pPROM. While this study was conducted in what was described as a homogenous Hispanic population in Chile, it may have implications in other populations.

A more recent study published in 2011 (Plunkett et al.) sought to identify genes that are involved in the timing of human parturition. Because of the relatively narrow birth canal and relatively large head in humans as compared to other primates, the authors theorized that genes that accelerate parturition and decrease the length of gestation to promote delivery through the passage of a smaller fetus might be identifiable. If the evolutionary changes that occurred to the genes could be found, they might hold the key to the onset of preterm labor and delivery among certain individuals. The researchers identified a novel gene, FSHR, that was identified as having an association with preterm birth and was found in African Americans. Although much more research is needed, there are early indicators that genomics and epigenomics are fields where scientific inquiry into preterm birth may provide elucidation of another component to the phenomenon of preterm birth.

The Life Course Perspective and Fetal Programming

Camara Phyllis Jones states, “race is a social classification in our race-conscious society that conditions most aspects of our daily lives” (Jones 2001:4). The life course perspective takes into account all factors that may impact health and wellbeing from the time of conception, and plays a role in understanding preterm birth. David Barker

(1990) and his associates hypothesized that fetal under-nutrition during pregnancy increased the risk of adult onset disease through poor programming of blood pressure regulation, cholesterol metabolism, and glycemic control. His contention is that what happens in the womb can lead to such conditions as hypertension, heart disease, obesity and diabetes in adulthood. This *fetal programming*, or systematic differences in experiences and exposures that begin at conception, may become embedded in the developmental biology and manifested later in life as racial/ethnic disparities in health. If fetal programming can affect adult health, it can also affect future reproductive potential (Lu and Halfon 2003).

In human and animal studies, perinatal stress is associated with high stress reactivity that persists well into adulthood. Theoretically, maternal stress could prime the immune system of her developing fetus with stress hormones leading to high stress reactivity and immune-inflammatory dysregulation that could increase her female offspring's vulnerability to preterm labor and low birth weight later on in life. This hypothesis can have very powerful implications. There appear to be critical periods of in utero development during which future reproductive potential is encoded (Lu and Halfon 2003).

“A child is more likely to be born low birth weight if her mother was born that way. If the cause is not a shared gene, perhaps it's a shared experience” (Kashef 2003). The immune system develops in utero and, according to Lu, during critical periods the immune system can be adversely affected by certain experiences and exposures, including repeated infections and undue stress (Kashef 2003). The result of these exposures can pattern the immune system in such a way that the risk increases for poor

health and birth outcomes. “A mother with less than optimal immune response may give birth to a baby with less than optimal immune response and so on” (Kashef 2003).

Cumulative pathway mechanisms provide an additional explanation for disparities in birth outcomes. “Maternal stress can cause increased release of norepinephrine and cortisol which then activates placental corticotrophin releasing hormone (CRH) gene expression, thereby precipitating the biological cascade leading to the onset of preterm labor” (Lu and Halfon 2003:14). Differential exposures to damaging physical and social environments at different life stages affect biological mechanisms over the life course.

A life course approach may, therefore, offer promise for future research. Examining the role of fetal programming and cumulative pathway mechanisms in birth outcomes would contribute additional insight and add to an increasingly larger body of knowledge regarding the etiologies that lead to prematurity. The life course perspective would not only reconceptualize determinants of birth outcomes longitudinally but would also allow for better understanding of the impact of race on birth outcomes within a life course context (Lu and Halfon 2003:19). The larger implications of race, though, first need to be understood.

A multitude of risk factors that are associated with preterm delivery have been examined in this section, and the risk factor that is consistently implicated in birth disparities is black race. In the next section, the meaning of race, and how it has become conflated with biology, is reviewed.

Race and Risk

The treatment of the topic of race is extensive in this work because it consistently remains the frontrunner in the list of variables that impact health disparities, particularly prematurity and low birth weight. As Copper et al. (1996) found, when controlling for all other factors, the classification of black race was a leading factor in explaining the difference in birth outcomes between blacks and whites. In all aspects of medical research in the United States, race figures prominently as the explanatory model for disparities in the incidence of disease and in health outcomes.

This review of race is evolutionary in nature. It covers the evolution of racial classifications, human evolution, and the evolution of anthropological thought regarding race from the points of view of anthropologists in the physical, biological, genetic and cultural disciplines.

The term *African American*, which first gained popularity in the late 1980s, is far more a reference to the descendents of those who were enslaved in the United States than to newly patriated citizens from the continent of Africa. But the term African American had many precursors. It was immediately preceded by *Afro-American*, a popular term in the 1970s during the height of the black power movement. Prior to that, a number of different terms were used. *Negro* was liberally used in scholarly, political, and social venues. While *Negro* was the official term for many decades, *colored* was commonly used in conversational English, particularly in the southern states. It was viewed as a polite term, as opposed to the derogatory “N” word, which remains unacceptable in any public forum.

Throughout this time, the simple term *black* has endured, and stood comfortably (and at times uncomfortably) alongside the other official designations for a people with a diverse heritage. In this paper, both *black* and *African American* will be used in reference to the population that is the focus of this discussion. A review of what race is, and is not, is an important first step in understanding how this categorization impacts concepts of risk and the explanatory models among African Americans.

An Anthropological Perspective on the History of Race

It may be difficult for those who believe in what I.A. Richards had called the Divine Right of Words to accept the suggestion that a word such as 'race,' which has exercised so evil a tyranny over the minds of men, should be permanently dethroned from the vocabulary, but that constitutes all the more reason for trying, remembering that the meaning of a word is the action it produces. [Ashley Montagu 1962]

Scientific inquiry into the understanding of humankind had its beginnings in the 1500s when Copernicus revealed a heliocentric (sun as center) view of the world as opposed to the long accepted Ptolemaic (2 C.E.) geocentric (earth as center) view. This new viewpoint led to a clash between religion and science. The reasoning was that if the earth was not the center of the universe, then perhaps God was not the ultimate reason, the cause or explanation of everything. The questioning of God led to the questioning of the church and, in particular, its oppressive role as a monarchy in France that caused the extreme suffering of the masses. This was the start of The Age of Enlightenment, or the age of reason, which led to the systematic study of the nature of man, and, consequently, the very beginning of anthropology.

There were many theorists of the past and present who contributed to the thinking today regarding race and human variation. Authors Mielke, Konigsberg and Relethford, in their book, *Human Biological Variation* (2006), chronicled this journey.

One of the earliest was Jean Brodin (1530-1596), who began to describe the differences in human beings by stature and temperament (*contrarie humour*), and used terms such as *strong, weak, hot, cold, dry, and moist*. He employed the Hippocratic “concept of humors,” which was purely descriptive, and based on outward appearances (Mielke et al. 2006).

Francois Bernier (1620-1688) wrote a more detailed description of humankind, and theorized that there were probably four or five species or races. The ones he described were Europeans, Africans (Negroes or blacks), Asians (far Easterners) and Lapps. Bernier is believed to have been the first in European history to describe race. At that time there was the concept of the *Great Chain of Being* which held that human diversity is ancient, permanent, and divinely ordered (Mielke et al. 2006:4).

However, Bernier did not have the impact of Carolus Linnaeus (Carl von Linné 1707-1778). Called “the Father of Taxonomy” and “the great classifier”, he originated the binomial nomenclature in the 1700s that is still used today to classify plants and animals (Linnaeus n.d.). In grouping humans, he not only gave physical descriptions, but also added other characteristics. Although he curiously gave nomenclature to some mythical creatures that he believed existed at the time, the ones listed below are those that relate to actually observed humans at that time and were strongly linked to geographic regions of the world (Mielke et al. 2006).

1. American (Americanus Rubescens)-These were American Indians, whom he described as red, choleric, upright, and ruled by habit: *regitur consuetudine*.
2. European (Europeus Albescens) -These were the white Europeans, whom he described as white, sanguine, muscular, and ruled by custom: *regitur ritibus*.

3. Asian (Asiaticus Fucus)- These were the Asians whom he described as pale, yellow, melancholy, stiff, and ruled by opinion: *regitur opinionibus*.

4. African (Africanus Negreus)- These were the black African people whom he described as black, phlegmatic, relaxed, and ruled by caprice: *regitur arbitio*.

[Mielke et al. 2006:5-6]

In these descriptions, Linnaeus mixed character with anatomy and chose to describe the black Africans as not utilizing logic, and having arbitrary means of determining behavior. Although Linnaeus was a Swiss botanist, many of the notable theorists of the time, including Brodin and Bernier, were of French origin. This was not surprising considering the fact that France was the birthplace of the Age of Enlightenment and the intellectual inquiry into the nature of humankind.

Next in this series of theorists was Georges Cuvier (1769-1832), who simplified the list slightly, to only three groups: black, white, and yellow, or Negroid, Caucasoid, and Mongoloid. Some have suggested that the reason this grouping of three has endured to the present is because of its connection to the frequent use of threes in the Bible, including the holy trinity. It has also been suggested that these three racial groups are descended from Noah through Ham, Shem, and Japheth (Brace 1996).

Although there were several key changes in the trajectory of the research, the evolution of thought was never linear. Samuel Stanhope Smith, a professor of moral philosophy and president of the College of New Jersey was a dissenting voice in racial typologies in the early 1800s. He did not believe in cultural evolution and did not believe that racial typologies were valid. He quite aptly pointed out that it was impossible to draw a distinct line between racial groups. Yet, even with his progressive

notions on the one hand, he was the philosopher who believed that if blacks continued to live in a climate more suited to Caucasians, they would turn white (Gould 1996:71).

Johann Friedrich Blumenbach, considered by some to be the father of anthropology, was, according to Gould (1996), the one who changed the focus of human order from being geographically based to the Caucasian ideal. He believed, since Noah's Ark landed on Mount Ararat in the mountains of Caucasus, that Caucasoids were the best representation of God's ideal human being. He said that other "races" degenerated from the Caucasoids as they moved geographically away from the Caucasus Mountains (Brace 1996). Oddly, however, Blumenbach did protest rankings based on beauty (a frog is beautiful to other frogs) or mental ability, and actually collected books written by blacks (Gould 1996).

While Blumenbach was ranking humankind, with Caucasians at the top, Alexander von Humboldt, in 1849, argued against ranking people on mental or aesthetic grounds. He was against slavery and any societal boundaries that impeded the attainment of what he termed "mental excellence". In order to explain why some societies seemed different from others, he simply concluded that some groups of people were more susceptible to culture than others.

The works of Charles Darwin also impacted ongoing discussions of race. Between 1842 and 1844 Darwin outlined his theory of natural selection, as a way of explaining adaptation and speciation. The premise was that the individuals best adapted to their environment are the ones most likely to survive and reproduce. With his theory of natural selection, any slight variation in trait, if useful, would be preserved. It is important to a note here, that Charles Darwin has often been erroneously credited

with the concept, “survival of the fittest.” That phrase is rightfully attributed to Herbert Spencer (Marks 2007).

Spencer believed that some groups of people were disadvantaged because of intrinsic flaws that explained their inferiority. He believed that humans adapted to their environments through the use of culture instead of through biological adaptation. He suggested that social inequality was not only inevitable but that it was actually desirable because people who are inherently inferior do not deserve any reward. He explained that just as the weaker animals in a stock die out to keep the herd strong, the poor must also be allowed to suffer and expire. He called this, “survival of the fittest,” and because his social theory was so similar to Darwin’s biological theory, it was called *Social Darwinism* (Marks 2007).

Darwin, however, believed in equality, and railed against mistreatment of blacks by Englishmen and their American descendants. He indicated that it made his blood boil to see what men did who professed to believe in God and love their neighbor. He stated, “If the misery of the poor be caused not by the laws of nature, but by our institutions, then great is our sin” (Gould 1996:27).

Stephen Gould, in his book, *The Mismeasure of Man* (1996), coined the term *biological determinism*, which he used to describe the concept that those people who were on the bottom were there because they were intrinsically inferior and that those on the top were there because they were intrinsically superior. This was a concept scientists endeavored to prove. During the 18th and 19th centuries many intellectuals justified slavery by affirming that whites were superior and blacks were inferior.

Abraham Lincoln proposed that due to physical differences, even though blacks were capable, whites should be in charge (Gould 1996).

While, up until the time of Charles Darwin, much of the speculation about human differences was based on observation alone, a key study by Samuel Morton, a Philadelphia physician and scientist, gave birth to scientific racism. Morton won worldwide respect for the “American school” of polygeny (Gould 1996:83). He gathered skulls from around the world with a hypothesis that a ranking of races could be established objectively by physical characteristics of the brain, particularly by size. Morton set out to establish a rank. (Gould 1996; Mielke et al. 2006)

There were two schools of thought at this time, the *monogenists* and the *polygenists*. Monogenism was the belief that all human life came from one single source, an “Adam and Eve”, and that races were products of degeneration. Polygenists held that races were separate biological species, or multiple “Adams” and ran in opposition to the scriptural version of the beginning of life. Louis Agassiz was a biologist who had been a monogenist, but when he came to the United States and observed blacks in the community, he decided that there must be multiple origins for human life (Gould 1996).

Agassiz and Morton, decided to work together to collect human skulls to measure brain capacities and then rank human races. From 1839 to 1849 Morton published three books on human skulls, which he believed gave irrefutable data on the mental worth of races. While white races were ranked highest with the largest brains, Indians and then blacks were ranked at the bottom with the smallest brains. When Gould painstakingly redid all of Morton’s measurements in the 1980s, he found them to be

completely erroneous. There were no differences between groups. Stephen Gould commented that it was obviously not accidental, “that a nation still practicing slavery and expelling its aboriginal inhabitants from their homelands should have provided a base for theories that blacks and Indians are separate species, inferior to whites” (Gould 1996:93)

Supporting the scientific racism of Morton and Agassiz was Etienne Seres, another French national. Seres did not believe in polygeny, or that there was a scientific justification for slavery, but he did see whites as more evolved than other races. He said that the adult Negro was comparable to the white child, and that the adult Mongolian was comparable to the white adolescent. In 1860, instead of measuring skulls, he completed a comparison of the measurement of the distance between the navel and the penis to document racial inferiority. By his measure, whites had the longest distance and were therefore the superior race (Gould 1996, Mielke et al. 2006).

The “cranial index” which was popularized by Anders Retzius in 1842, was a measurement of the maximum breadth of the cranium, divided by the maximum length. These measurements were then used to categorize skull types and develop “ideal types” of races. It was thought skull shapes were resistant to change and “would be an excellent feature for tracing a population’s (and also an individual’s) ancestry and origin” (Mielke et al. 2006:11). However, this assumption was incorrect. Long before Gould refuted the results of Morton and Agassiz, another anthropologist showed that cranial measurements were meaningless.

German-born anthropologist Franz Boas (1858-1942) introduced a scientific approach to anthropology that established the four currently accepted subfields—linguistics, physical, cultural, and archaeology—and shaped modern American anthropology. Rejecting the evolutionist theories of the past, Boas and his students set the tone for the manner in which anthropological inquiry in America would be approached for years to come (Moore 1997). Boas limited race's meaning to biophysical and morphological characteristics and divorced it from the learned behavior of language and culture. He measured over 17,000 crania and showed that the cephalic index and other features could undergo drastic changes from one generation to another depending on the environment. Among anthropologists of his time, it seemed that Boas was a voice in the wilderness. But it was not only through science that he worked hard to change racist thought. In 1931 he gave his presidential address to the American Association for the Advancement of Science, entitled "Race and Progress," and further worked to help establish the NAACP (Moore, 1997:47).

Despite the strong protestations of Boas, Ales Hrdlicka, who founded the American Journal of Physical Anthropology, was another strong proponent of scientific racism. Hrdlicka organized the division of physical anthropology at the U.S. National Museum, which later became the Smithsonian. He then was the curator of the Smithsonian from 1910 to 1942, and once stated that the real problem of the Negro lay in his brain, and that that should be the focus of scientific inquiry. In 1927, Hrdlicka published findings that the Negro race was phylogenetically closer to primitive man than the white race (American Anthropological Association 2007). According to Mukhopadhyay and Moses, "this racial world view also provided a rationale for slavery,

colonialism and neocolonial domination, racial segregation, discrimination and miscegenation laws, and fueled the eugenics and ant-immigration movements” (1997:516).

Ernest Albert Hooten perpetuated the typological approach to human variation that was supported by many physical anthropologists of the time. Although a well-respected and well-published Harvard professor, “perhaps more than any other scientist of his time, Hooten did more to establish racial stereotypes about black athleticism, and black criminality from an anthropological framework” (AAA, 2007). In his 1926 book, *Up From Apes*, he identified what he believed to be the morphological characteristics of the “primary races” and “subtypes” of those races. Certain metrical and morphological traits were used to “solidify the image that races were discrete units that were homogenous in their characteristics” (Mielke et al. 2006:12). He believed in biological and racial determinism, and his many writings supported this theory.

During this same period, however, there were scientists moving in another direction. Hirschfeld and Hirschfeld suggested that ABO blood groups could be used to delineate racial groups and actually came up with six different types. This new trajectory was viewed as a promising one. In 1926, Snyder (Mielke et al. 2006) identified seven races and argued that blood group data should be used as additional criteria for racial classifications. He said that the advantages were their heritability, their stability under varying environments, the fact that conscious selection for blood group type was not possible, and that variations in racial groups correlated with racial affinities (Mielke et al. 2006:13).

Ashley Montagu, author of *Man's Most Dangerous Myth: The Fallacy of Race* (1942), was probably next to change the focus when he contended that the term *race* should be discarded altogether. Montagu, an anthropologist, and Julian Huxley, a biologist, argued that zoological nomenclature should not be used for classifying human beings (Mielke et al. 2006). Following the lead of T.H. Huxley in 1865, and Joseph Deniker in 1900, Montagu adopted the term *ethnic group* in 1936 because he contended that *race* had lost its usefulness in describing human variability. He also stated that the term *race* closes the door on the discussion, while *ethnic group* at least leaves the door a bit ajar (Montagu 1976). Montagu did not deny differences in populations, but emphasized that the boundaries were not clear.

Following that line of reasoning, Henry Fairchild, 1944 presented seven arguments against racist thinking:

1. That all men have a common origin.
2. That men of all races are more alike than different.
3. That there are greater differences between the extremes of a given race, than there are between the average types of different races.
4. That because the extremes of races overlap, individuals in one race may have a particular trait more highly developed than some individuals belonging to some other race of which it is supposed to be characteristic.
5. That there are no pure races today
6. That all the races of men can interbreed, and that such miscegenation is not harmful.

7. That intelligence tests do not reveal simple native ability but are influenced by education and other environmental factors. [Mielke et al. 2006:14]

In 1944 Dobzhansky attempted to provide a genetic definition of race. He described races as populations with differing incidences of certain genes, but that they could exchange genes over whatever boundaries separated them (Dunn and Dobzhansky 1952:265). He also proposed that, "Races can be defined as populations that differ in the frequencies of some gene or genes" (Dunn and Dobzhansky 1952:118).

Moving this concept forward, William Boyd, in 1950, argued that anthropometric measurements must be discarded and replaced with a new genetic perspective. He noted that a person may be considered inferior, if, for example, he has dark skin, but in no part of the world would his blood gene group exclude him from the best of society. He favored the genetic perspective for reasons including the fact that (1) skeletal morphology is difficult to determine in living beings, (2) the skeleton adapts quickly to environmental conditions, (3) skeletal characteristics are controlled by the action of many genes, and (4) that metric studies of the past were not logically conceived, so anthropometry and craniometry are obsolete (Mielke et al. 2006:15).

When Sherwood Washburn, in 1951 wrote an important article redirecting the focus of physical anthropologists, titled *the New Physical Anthropology* (Mielke et al. 2006), in which he said the old methods of taking careful measures and defining type specimens for static classification was over, he emphasized that the new physical anthropology should focus on mechanisms of evolutionary change. Anthropologists began arguing that populations, breeding units, should be the basic unit of study of human diversity because races were not static and were not fixed entities.

It would seem appropriate to diverge very briefly here to address the mechanisms of evolutionary change that Washburn referenced. However, in order to do so, a short treatment of evolution is in order.

Although controversy continues, there are two primary models of how modern humans evolved: the multiregional model and monogenesis model. With the multiregional model, the theory is that modern humans evolved in parallel in different parts of the world. This theory proposes that the geographic diversity of humans originated between one and two million years ago when *Homo erectus* spread from Africa into the other continents (Campbell 1996:660). This model identifies gene flow, or the occasional interbreeding among neighboring populations as the explanation for the great genetic similarity of all modern people.

However, the monogenesis or “Out of Africa” model is supported by many anthropologists today. Christopher Stringer, a paleoanthropologist from the University College, London was one of a group of anthropologists who disagreed with multiregional model and supported a different assumption (Campbell 1996). According to the monogenesis model, “modern humanity did not emerge in many different parts of the world, but only in Africa, from which humans dispersed relatively recently” (Campbell 1996: 660). With this model, geographical diversification of modern humans occurred within just the past 100,000 years, in contrast to the 1 million years for the multiregional model. The most compelling argument for Stringer’s position is that “only African fossils chronicle the complete transition from archaic *Homo sapiens* to modern humans” (Campbell 1996: 660). The monogenesis theory has also been called “the replacement model” because of the assumption that *H. sapiens* were not

contemporaries of *H. erectus*, but actually replaced them. The replacement model emphasizes that *H sapiens* descended from a single common ancestral group and therefore explains the reason that diversity among modern humans is minimal (Campbell 1996).

Research conducted by Rebecca Cann and Allan Wilson from the University of California Berkley further validated the monogenesis theory. They examined the mitochondrial DNA (mtDNA) of living humans from a total of 147 women from Asia, Africa, Europe, Australia, and New Guinea. They found that African women tended to be more heterogeneous, suggesting that mutations had a long time to accumulate, while in other populations the mtDNA was more uniform (Scupin and Decorse 2001:121). This was significant because “the greater the difference between the mtDNA of two people the longer ago that mtDNA diverged from a common source” (Campbell 1996:660). The research by Cann and Wilson traced the source of the mtDNA of all human populations back to Africa (Scupin and Decorse 2001).

No one knows exactly what the modern human was like whose mtDNA was traced back 130,000 to 200,000 years ago, but it has been established that biodiversity began early on. This shift occurred through the four forces of evolution: mutation, gene flow, genetic drift and natural selection. *Mutation* can be described as an alteration of genetic material at the cellular level that can occur randomly, and is significant in evolution because it is the only source of new genetic material (Scupin and Decorse 2001:61). Mutation rates, however, are very low and therefore are not a major source of changes in allele frequencies in a population (Scupin and Decorse 2001).

The next force, *gene flow*, is “the exchange of alleles between populations” (Scupin and Decorse 2001:61). Through interbreeding, or intermarriage, new genetic material is introduced, resulting in changes in the allele frequencies in a population. Gene flow acts by homogenizing neighboring groups (Marks 1994) and therefore decreases variation between populations. The long history of migration and the reproductive connections between different populations is the reason there is now minimal genetic distance among humans (Scupin and Decorse 2001).

Genetic drift is the “evolutionary change resulting from random sampling phenomena that eliminate or maintain certain alleles in a gene pool” (Scupin and Decorse 2001). In the process of reproduction there is the chance selection of genetic material. Though non-adaptive, this results in changes in allele frequencies from one generation to another (Scupin and Decorse 2001).

Natural selection, which adapts populations to local circumstance (Marks 1994) is said to provide the key to evolution. It can be defined as the changes in the allele frequencies of a population which result from differences in reproductive success. “Certain alleles may be selected for environmental advantage. These may help an organism to resist disease better, obtain food more efficiently, or avoid predators more effectively”(Scupin and Decorse 2001:62). With natural selection, the selective pressures of the environment drive the changes.

When Washburn exhorted physical anthropologists to refocus their study of human diversity based on the evolutionary forces described above, his ideas were in concert with the notion of discarding racial categories. This concept was more recently addressed and summarized by biologist and geneticist Alan Templeton. He explained

that whether we are looking at past or present day populations, the use of racial categories in structuring our samples hinders, not helps, our efforts to describe human variation and explain its causes. Genetic loci consistently show patterns that are discordant with racial typologies.

Because of the extensive evidence for genetic interchange through population movements and recurrent gene flow going back at least hundreds of thousands of years ago, there is only one evolutionary lineage of humanity and there are no subspecies or races under either the traditional or phylogenetic definitions. Human evolution and population structure have been and are characterized by many locally differentiated populations coexisting at any given time, but with sufficient genetic contact to make all of humanity a single lineage sharing a common, long term evolutionary fate. [Templeton 1999: 647]

In 1962, Ashley Montagu shared his impassioned beliefs as to why the term *race* must be eliminated from all scholarly work while discussing various terms suggested by other authors. He also admonished that the layman's view of race remained entrenched, erroneously concluding that there is an indissoluble relationship between mental and physical characteristics that make individual persons of certain races superior or inferior to the members of certain other races. He stated that "the term 'race' takes for granted what should be a matter for inquiry" (Montagu, 1962:434). He did not believe that the term *race* should be retained and redefined because he said it would still "enshrine the errors it was designed to erase" (Montagu 1962:435). He was frustrated by its misuse, overuse, ambiguousness, and the fact that it was a loaded term that mixed intelligence, personality, culture and biology (Mielke et al. 2006:18). He warned against artful dodging in the use of the term *race*, and stated that, "one cannot combat racism by enclosing the word in quotes" (Montagu 1962:434).

While suggesting such terms are *genogroup*, or *geographical genogroup* as being a more accurate representation of a population, he had a preference for the term

ethnic group. He defined an ethnic group as “one of a number of breeding populations which together comprise the species *Homo sapiens* and which individually maintain their differences, physical and genetic and cultural, by means of isolating mechanisms such as geographic and social barriers” (Montagu 1962:435).

A firm hold of “race”, however, was not to be relinquished. Garn and Coon, in 1955, held that there were three levels of racial groups: geographical, local and microraces. In 1962, Carlton Coon published the book, *The Origin of the Races*, in which he identified five races of people: Caucasoids, Mongoloids, Australoids, (and Dwarf Australoids), full size Congoids (African Negroids) and dwarf Congoids (African pygmies) and Capoids (bushmen and Hottentots). In 1965 he published the *Living Races*, insisting that there were five original pure races, a theory proven to be totally inaccurate (Rensberger 1981).

Frank Livingstone tried to put an end to the term “race” once and for all. He published the article “On the Non-Existence of Races” and said that research should focus on geographical variations of trait (Mielke et al. 2006). He taught that what should be studied is clinal variation, which is the gradual change in phenotype and genotype over geographic space. He said that, “there are no races, only clines” (Livingstone 1962:279).

The controversies in physical anthropology over the past two centuries are still not resolved today. Although many thought that with the human genome project, archaic taxonomies would be abandoned, this has not happened. Mukhopadhyay and Moses (1997) point out that the debate continues with those wishing to use race to refer to the biology of biodiversity and ethnicity to refer to cultural expression. These authors

contend that cultural and physical anthropologists need to work together to explain to the public at large that race is a social construct and to eradicate it from the worldview. They describe racial classifications as the most archaic, scientifically unfounded and socially pernicious aspects of 19th- and 20th- century essentialist typologies.

Anthropologist Audrey Smedley, in her discussion of race and the construction of human identity, stated that race has been used to “transform perceptions of human difference based on notions of heredity and permanence” (Smedley 1999:693), something that was unknown prior to the 17th century. By imposing social meaning on physical variations among human groups this became the basis for the structuring of the total society.

The impact of this experience touches all aspects of the lives of African Americans. She refers to a “transgenerational retention and transmission of an ethos of hopelessness” (Smedley 1999:698) and emphasizes that the continued use of “race” has nothing to do with physical qualities of a population, “but everything to do with the allocation of power, privilege and wealth among them” (Smedley 1999:699).

Matt Cartmill (1999) says that while researchers want to continue to use the race concept to express human variation according to geography, racial categories are biologically incoherent and misleading. Races are not geographically distinct and are not phenotypically distinct. He sees the endurance of race as being a way to keep the wealthy and powerful on top and to absolve them from resolving social inequalities because they are the natural order of things.

Throughout Western history, the wealthy and powerful have found it comfortable and expedient to overestimate the importance of heredity in explaining the differences between people, in order to try to reassure themselves and persuade others that the prevailing social inequalities are just and natural. In most or all

complex societies, the ascription of social status has been to some degree hereditary, and membership in low status classes or castes has been widely regarded as a matter of simple inheritance as though poverty, ignorance, and powerlessness were the dominant alleles at a single gene loci. [Cartmill 1999:656]

Biological Anthropology and Race

Loring Brace, in his article “A Four Letter Word Called Race,” explains that the genesis of biological anthropology was rooted in the assumptions that there are valid biological entities called “races” and that they are legitimate targets of anthropological inquiry (Brace 1996:106). Noting that biological anthropologists have been slower than many in the field to recognize that these entities do not have coherent biological reality, he suggests that while human biological variation is real, “races” cannot be used for comparison. Instead, traits that are important for human survival are distributed clinally, according to the selective forces that govern their expression (Brace 1996:106). He advocates that the distribution of individual traits and the selective pressures modifying these traits should be the focus for studying human diversity, not arbitrary entities of race (Brace 1996).

Jonathan Marks, a molecular anthropologist, has written and spoken extensively on the issue of race. He asserts that race is a social construction that has no biological referent. There is no biological validity to the racial classification that persists today. He said that when geneticists say that there is no such thing as race, they are referring to the fact that there is no validity in the current classifications (Marks 2000). There may well be certain sets of genetic variants that can be used to develop racial categories, but the question would then become how many common genes does it take to make race,

and which genes should be the determining factors. These are very complex questions to which there are currently no answers.

Marks also speaks of many misconceptions about race. First, the idea that a race can be determined by phenotype makes no sense. Phenotype is underdetermined by genotype. In other words, what is on the inside is not directly related in any way to what is on the outside. Secondly, genes are inherited independently, which is why a person can have the dark skin of an African, the straight black hair of an Indian, and the nose shape of a European (Marks 2007). The third is probably the most insidious of the misconceptions, and it is that our role in society is biologically determined. This was a position held by E. A. Hooten when he developed his racial typologies, and E.O. Wilson, a sociobiologist who shared Hooten's belief on the nature versus nurture controversy. Wilson, from his study of ants, believed that in societies, the roles individuals played were directly related to their biological capabilities. Marks, however, explains that the roles seen in society are primarily held as a result of opportunity, not biology.

As an example, he points to the fact that in the 1920s there were many Jewish boxers, and in the 1940s many could be seen on the basketball court. However, as opportunities for them increased, he commented that they were more likely to enter medical school than the boxing ring. Marks uses this example to show why the long held concept that blacks excel in sports due to some biological advantage is erroneous. In many institutions in the United States the doors to some careers are closed to blacks, but for certain sports, the doors are wide open. That is one reason so many young African Americans aspire and work toward success in athletics. They share a common experience of limited opportunities, regardless of their talents or specific heritage.

African Americans differ in color, in identification with the variants in African American culture, in place of ancestral roots, in educational attainment, in employment opportunities, in level of income, in quality and location of residence, in religious preference, in commitment to political views and party affiliations, in range and intimacy of contact with whites, and in range and intimacy of contact with other African Americans. However, what African Americans share is a history of enslavement, acculturation, and racial oppression which gives relevance to the initial bond of their African heritage. African Americans continue to be singled out from others in the society in which they live for differential and unequal treatment and consider themselves subjects of collective discrimination. [Scott 1995:1]

Racism is a part of the common historical experience in America. Race, in all its overt and nuanced forms is not just a fact in shaping the lives of African Americans, it is the major factor.

Race and Health Disparities Research

African Americans have higher mortality rates than non-Hispanic whites for virtually every major disease, and in the area of infant health, infant mortality rates between African American and white infants have actually widened in the past 50 years. Joseph L. Graves, in his book *The Emperor's New Clothes*, wrote a chapter entitled "Race and the Disease Fallacy" (Graves 2005). He argues that the varied ancestry of African Americans should give them a heterozygote advantage (through natural selection and genetic drift) against disease. Yet a biological explanation has not been substantiated. "One of the most deleterious consequences of attributing unexplained variation to genetic effect is that it absolves the researcher of further investigation into more complex social/environmental influences" (Williams and David 1997:446).

A key message in the article by Reanne Frank, "The Role of Biology in Contributing to Race/Ethnic Disparities", can be summarized in this one quotation: "human biological variation is not racially patterned" (Frank 2001:443). Her focus in this

article is on the imperative that researchers readjust the manner in which they approach studies of disparities and end the long held practice of conflating biology with race. She points to the misunderstanding that there is a genetic basis to race, and says that in order to reconceptualize the role of biology in contributing to race/ethnic differences, the first step is to clarify the nature of human biological variation (Frank 2001: 443).

While confirming that biological differences do exist between people and between populations, Frank emphasizes that these differences are not racially patterned. She refers to the evolutionary forces of natural selection, genetic drift and gene flow. First, natural selection is simply the genetic response to local conditions. Consequently the changes produced are adaptive and are the result of evolutionary responses to selective forces. “They are not restrictive to a particular gene pool, for the selective force that brought them about could have operated in the same intensity on a different gene pool” (Frank 2001: 444). These clines demonstrate that human variation exists because of the selective forces that maintain these variations, and not because an individual belongs to a certain racial group (Frank 2001:444).

The second force she discusses is genetic drift. Genetic drift is the process of perpetuating trivial traits through heredity. Loring Brace (1996) refers to these as “cluster traits.” There are traits that seem to be associated with one another and are found in certain geographic locations. Cluster traits may be used to group or compare human populations, “without the attendant danger of creating anything comparable to racial typology” (Brace and Hunt 1990:343-345).

The third force or process is gene flow. This is the sharing of genes across neighboring populations. However, Kieta and Kittle (1997) warn that racialized thinking

can incorrectly identify gene flow as the explanation for finding common traits between populations. “When traits that are predefined as belonging to different groups are found in combination, admixture is incorrectly understood to be the only explanation” (Frank 2001:445).

An alternative model is presented that specifies the role of biology in contributing to race/ethnic disparities in health and mortality without reinforcing a biological conceptualization of race (Frank 2001). “The essential problem underlying a biological concept of race is that it runs afoul of the available scientific evidence that shows that racial categories are incapable of appropriately capturing biological distinctiveness” (Frank 2001:443) Camara Phyllis Jones uses the analogy of slicing a pie to make this same argument. “There is no denying that there is genetic variability on the planet. However the pie slicer that we call race does not capture that genetic variability” (Jones 2001:299)

Using prematurity and low birth weight as an example, Frank contends that researchers need to investigate the more mutable biologic origins of disparities, such as determining how the physiological pathways for growth are impacted by social influences and the environment. Understanding how racial classifications can have a direct impact on the distribution of risk and opportunity (Jones 2001), it can be concluded that “the overriding importance of race in contributing to race/ethnic disparities in health is that it functions as an excellent measure of exposure to racism” (Frank 2001:449).

If researchers do indeed share a commitment to the elimination of racial disparities in health outcomes then their first step is to stop using an outdated conceptual framework to understand these differences. Until this is done, the deleterious scientific and social consequences that have cumulatively resulted

and continue to result from the irresponsible use of race in health research should lie on the conscience and mar the academic credibility of each and every researcher who uncritically utilizes a biological concept of race in their analyses, findings or conclusions. [Frank 2001: 453]

James Trostle, both an anthropologist and epidemiologist, provides a cohesive description of the problem of race and health research in America in his review of race as a cultural category and a risk factor for ill health. The Library of Congress reported that from 1990 to 1996 race or ethnicity was commonly cited in infant mortality studies (80 percent) in the United States, while it was far less common (20 percent) in studies outside the United States. Additionally, categories of race were found in 50 percent of 914 articles in the American Journal of Public Health (AJPH) between 1980 and 1989, but less than 8 percent included clear definition of those terms. And this is the problem. While researchers frequently refer to race or ethnicity in their reports, the categories are either not defined or poorly and inconsistently defined.

Even if race were somehow defined in these writings, Trostle explains that race cannot capture and explain human variability. Genetic variation is widespread and gradual. There are no sharp geographic differences that clearly separate racial groups. Genetic variation exists in many characteristics other than skin tone, and there is no packet of physical characteristics that vary consistently with skin tone. Classifying people into races based on skin color is arbitrary, and no single physical trait can encompass human diversity. He asks the question, “What sort of human variability is being measured if the categories include both skin color, and geographic origin, are based on self-assessment, and change over time?” (Trostle 2005:57) Racial classifications become meaningless because they change from one generation to another, making comparisons between earlier and later studies invalid.

Being black in the United States does not mean having different genes than those who are white, because, as confirmed by the findings of evolutionary biologist Richard Lewontin, there is more genetic variation within groups than between groups (Lewontin 1972). In 1972 Lewontin concluded that only 6.3 percent of human diversity is attributable to race and that 84.5 percent of the variation occurred within the selected population groups classically identified as races (Brown and Armelagos 2001:35).

Being black does, however, “often imply having lower socioeconomic status, lower educational attainment, reduced access to health and housing services, exposure to environmental contamination, inadequate or nonexistent health insurance, and differential treatment by police, and health personnel” (Trostle 2005:58). Trostle poses the question as to why race continues to be so widely used in public health and medical research when the theoretical foundation is so poor. His answer was that in a racially stratified society, there are clear biological effects to the way in which people are sorted, and that these social categories of “race” set them on different life trajectories (Trostle 2005:58). This, in turn, influences their earning potential, educational achievement, access to health services, occupation, and lifestyles, which result in measurable biological outcomes (Trostle 2005:58). He concludes that, “in order to identify and intervene in health disparities, it is useful to collect information by ‘race’ if only to see the effects of racism” (Trostle 2005:58). This must be accomplished, however, without giving the misleading impression that biology, and not oppression and discrimination, are at the root of the health problems.

“While socioeconomic factors are understood to be important driving forces in determining differential health outcomes, they are not usually understood to directly

affect health, but rather they largely operate through a host of proximate or intervening factors such as medical care, social support, levels of stress, nutrition, substance abuse, exercise, and other health behaviors” (Williams and David 1997:451).

Medical Anthropology and Race

Amongst medical anthropologists there are varying theories regarding race. According to Mary Douglas, it has been the very nature of humans to classify, and in the introduction to her 2004 reproduction of her classic 1966 book *Purity and Danger*, Douglas writes “rational behavior involves classification, and classifying is universal” (Douglas 2004:xvii). She further contends that “organizing requires classification, and that classification is at the basis of human coordination” (Douglas 2004:xvii).

Her theories, as an anthropologist, help inform the rationale behind the complex, absurd, and enduring categorization of people into races in this country. She said that in the chaos of shifting impressions, each of us constructs a stable world in which objects have recognizable shapes, are located in depth and have permanence. “Our pollution behavior is the reaction which condemns any object or ideal likely to confuse or contradict cherished classifications” (Douglas 2004:45)

Why blacks have become such an object as the undesirable is somewhat further explained by Sander Gilman (1985) in his discussion of stereotypes. Beyond the white-black, good-bad mentality suggested by Douglas, Gilman contends that stereotypes are a universal means of coping with anxieties engendered by an inability to control the world around us. He contends that we create images that we both glorify and fear (Gilman 1985:15). There is an innate need to explain difference, the Other, and it is inevitable and ungovernable. Although there is no racial pattern to human biological

variation (Frank 2001:443), Gilman tells of how science creates fiction to explain facts, and an important criterion for endorsing the fiction is its ideological acceptability. Simply put, it is comforting to those who support racist practices to justify them scientifically. Further, Gilman states that the reception of a scientific reality is based on whether it fits within the web of conventions of the representational systems of the given culture (Gilman 1985:28). This concept helps to explain the continuing effort among certain scientists to prove the biologic/genetic inferiority of African Americans.

Mary Douglas said that people need hard lines and clear distinctions to order their thinking. People objectify the other and place “bad” connotations and “good” connotations as it fits their cultural and experiential needs (Douglas 2004). Once we have put people in categories, we need to keep them there to maintain our ordered thinking. But what is the enduring legacy of racist thinking and a racist society? The consequence, as described above, is an alarming disparity in health outcomes.

Lock and Scheper-Hughes suggest that it is medical anthropology’s engagement with the body that distinguishes it both from other anthropology subdisciplines and the biomedical sciences. They state that what is special to medical anthropology is “the sentient human body” (Lock and Scheper-Hughes 1996:44). However, they describe this human body as actually a relation of three bodies: the individual body, the social body, and the body politic (Lock and Scheper-Hughes 1996:45).

The first of these three is the *individual body*. This is the embodied self, existing apart from other bodies. Clifford Geertz comments that the western conception of the person as a bounded unique cognitive universe is a peculiar idea in the context of world’s cultures (Geertz 1984:124). However the individual self is viewed, though,

whether separate or fused with society, that position affects the individual's concept of health and illness. The next body is the *social body*. Important to medical anthropology are the many conceptions of an equivalency between a healthy body and a healthy society or a diseased body and a malfunctioning society. Beliefs in many cultures link the health or illness of the individual body to the social body. The third body is the *body politic*, which refers to the external regulations, surveillance and control of human bodies. There are codes and social scripts to domesticate and conform the individual body to the needs of the social and political order (Lock and Scheper-Hughes 1996:63). All three of these bodies have relevance to the concern of prematurity and low birth weight.

Camara Phyllis Jones (2000) describes three levels of racism—institutionalized, personally mediated, and internalized—and their relationship to health outcomes. These three levels correspond in reverse order to the three bodies. Institutionalized correlates with the body politic, personally mediated correlates with the social body, and internalized correlates with the individual body. Suggesting that race is only a rough proxy for socioeconomic status, culture, and genes, Jones says that it does, however, precisely capture the social classification of people in a race conscious society such as the United States. She further comments that the race that is noted on a health form, by a sales clerk, a police officer, or a judge, has a profound effect on daily life experiences in this country. She concludes that the variable “race” is not a biological construct that reflects innate differences but a social construct that captures the impact of racism.

Institutionalized racism is that which manifests itself in both material conditions and access to power. This would include housing, education and job opportunities, government representation, and access to resources.

Personally mediated racism is what is typically referred to as prejudice or discrimination, the experience of mistreatment on the basis of race. This can be manifested as poor service, suspicion by shopkeepers, purse clutching, dehumanization (police brutality hate crimes) and scapegoating.

Finally, internalized racism is the acceptance by members of the stigmatized group of negative messages about their own abilities and intrinsic worth. It involves accepting limitations; distrust and prejudices against others in one's own group; embracing the dominant culture's standards of beauty while devaluing one's own; use of self-targeted racial slurs; hopelessness; and a sense of helplessness (Jones 2000). Jones challenges public health researchers to study these three distinct levels of racism, and to vigorously strive to determine how each adversely compromises the health status of African Americans.

Antonio Gramsci in the 1940s coined the term *hegemony* to describe the preponderant authority, or dominance, socially, culturally, ideologically and economically of one group over another in a society. "Political and intellectual leaders of a society create a system of beliefs and ideas that are accepted by the common people and which help maintain the power of the ruling class" (McGee and Warmus: 554). An acceptance at some level, has been and still is a part of the belief system of many African Americans. Martin Delany said, "A child born under depression has all the elements of servility in his constitution" (Delany 2009:97).

Carter G. Woodson, in his 1933 book *The Mis-Education of the Negro*, specifically references the deliberate intent to teach inferiority to blacks in order to assure their quiet submission in unequal treatment. He states, “When you control a man’s thinking, you do not have to worry about his actions. You do not have to tell him not to stand here or go yonder. He will find his ‘proper place’ and will stay in it. You do not need to send him to the back door, he will go without being told” (Woodson 1933:xiii).

Lock and Scheper-Hughes address this situation in their discussion of body praxis, defined as “someone living out and reacting to his or her assigned place in the social order.” Physical distress and illness can also be thought of as acts of refusal, or of mockery, a form of protest (albeit unconscious) against oppressive social roles and ideologies (Lock and Scheper-Hughes 1996).

All the data presented thus far points to a need for greater understanding of how birth outcome disparities are impacted by the classification of race (Douglas 2004) and how the individual, social and political bodies experience that classification. Leith Mullings makes this observation and appeal:

As a discipline, anthropology still remains largely on the periphery of studies of racism. Anthropologists, with notable exceptions, rarely use the term ‘racism’ and despite a range of scholarship relevant to this I argue that anthropologically informed and ethnographically sensitive studies can potentially illuminate the way in which contemporary institutions, policies and structures reproduce racial inequality without overtly targeting its victims.[Mullings 2005:679]

CHAPTER 2

STRESS, RACISM AND AFRICAN AMERICAN WOMEN'S HEALTH

Only the black woman can say, "When and where I enter, in the quiet undisputed dignity of my womanhood, without violence and without suing or special patronage, then and there the whole (black) race enters with me." [Anna Julia Cooper 1892]

In order to understand how being an African American woman can impact the rate of preterm and low birth weight infants in this country, it is first important to understand what it means to be black in America, and how that racial classification affects health. There is both the national, biomedical explanation and there is the explanatory model that emerges from the level of the individual.

In studies of race and health, racism and discrimination have frequently been invoked as explanations for the high rate of morbidity and mortality among African Americans (Jackson et al. 2002). According to Jackson et al. (2002), racism can affect the health status of African Americans in four basic ways. First, racism leads to differential treatment, resulting in a difference in the quality and quantity of health care. Second, racism and discrimination cause differences in life chances and living conditions, resulting in the low socioeconomic status (SES) that remains a persistent, but not clearly elucidated, risk factor for numerous health problems. Third, the experience of specific incidents of unfair treatment can generate psychic distress and other physiological mechanisms that adversely affect health. Finally, the coping strategies people use when grappling with inequitable living conditions and a hostile psychosocial environment (such as internalizing negative stereotypes or substance abuse), may also impair physical and psychological functioning. In 1984, Fernando

proposed that, “racial discrimination is more than an added stress, it is a pathogen that affects health” (Jackson et al. 2002).

Racism is operationally defined by psychologist Rodney Clark, in his article “Racism as a Stressor for African Americans”, as “beliefs, attitudes, institutional arrangements and acts that tend to denigrate individuals or groups because of phenotypic characteristics or ethnic group affiliation” (Clark et al.1999:805). While there is no a priori way of determining if an environmental stimulus will be perceived as racist by an individual (Dressler 1988), chronic and acute exposure to perceived racism may differentially predict self-reported health status, and contribute to psychological and physiological sequelae that may be particularly toxic to African Americans (Clark et al. 1999). *Perceived racism* refers to the subjective experience of prejudice or discrimination (Williams and Jackson 1997). *Racism-specific* coping mechanisms, both active and passive, have been examined and found to be related to increased psychological stress, poorer well being and more chronic conditions among African Americans (Williams et al. 1997). In 1996 Dr. Vetta Sanders Thompson, a psychologist who has focused on racial identity and health disparities, published research that showed that “racism, like other stressful life events, produces measurable reports of subjective distress. The presence of intrusion and avoidance symptoms suggest a reaction similar to posttraumatic stress disorder” (Thompson 1996:231).

The physiological responses that follow exposure to psychologically stressful stimuli involve immune, neuroendocrine and cardiovascular functioning. When exposed to chronic stress, the adrenal gland produces hormones that suppress the activity of B-lymphocytes and T-lymphocytes, thus preventing the body from destroying or

neutralizing foreign substances and increasing vulnerability to disease. Research suggests that immune responses to chronic and acute stress are not transient (Stone et al. 1993). When coping mechanisms do not attenuate stress responses, they are considered maladaptive, and may negatively affect health (Burchfield 1985; Clark and Harrell 1982). On the other hand, adaptive coping responses are postulated to mitigate enduring psychological and physiological stress, thereby reducing the potentially negative impact of racism on health (Clark et al. 1999). African American females are especially at risk for maladaptive coping from the dual pressures of racism, and sociocultural performance expectations.

Jones and Gooden in their book *Shifting, The Double Lives of Black Women in America*, described their “African American Women’s Voices Project” as being research that entailed “listening very closely to how Black women make sense of their lives, to the words and voices they use to evoke their experiences” (Jones and Gooden 2003:5). They further explained that it was of the utmost importance to look at the pressures with which black women cope. They described how African American women must constantly shift between the various roles expected by society and execute them all masterfully. “The expectations that black women will be available to nurture and take care of others while subsuming their own needs and wants, the lack of affirmation or mirroring by the larger society, the multiple demands, the multiplicity of roles, the curtailed opportunities—all of these factors which fuel shifting can contribute to chronic feelings of emotional exhaustion, hopelessness, and despair” (Jones and Gooden 2003:130).

Greene et al. (2000) describe how African American women are affected by low self-esteem, frustration, and a personal devaluation that is an expression of internalized racism. Standards of beauty that are inconsistent with the normal phenotype of many African American women lead to struggles to conform that are emotionally costly. “In a racist society, some portion of the oppressed group will seek acceptance by borrowing and internalizing the dominant society’s ideology” (Jackson et al. 2002:7). This type of response, according to Akbar (1991) can lead to pathogenic consequences as a result of what he calls an *alien-self disorder*, in which oppressed groups adopt the attitudes, beliefs and behavior of the dominant group.

Second, adding to this self-esteem issue are difficulties associated with what can be referred to as “the icon of the strong black woman” (Romero et al. 2000). Maya Angelou, in her book, *Wouldn’t Take Nothing for My Journey Now*, alludes to this need to never show weakness in telling a story of how her grandmother had no tolerance for people who complained. She quoted her as saying, “What you’re supposed to do when you don’t like a thing is change it. If you can’t change it, change the way you think about it. Don’t complain”(Angelou 1993:87). This type of sage wisdom, handed down from generation to generation of African American women, begins as an empowering admonition, but then proceeds to encourage a form of acceptance. Following an experience she had that highlighted race and the insidious nature of racism, Angelou shared a poem, one stanza of which reads:

*I note the obvious differences
Between each sort and type
But we are more alike my friends
Than we are unlike. [Angelou 1993:125]*

Maya Angelou utilized her writing as a means to cope with the stressful experience of a thoughtless, racist remark. Despite suffering a lifetime of racial insults, the African American woman is culturally bound to demonstrate enduring strength. Romero et al. (2000) state that there are two themes to the icon of the strong black woman. The first is that the African American woman is strong, self-reliant and self-contained. The second is that her role is to nurture and preserve the family. Striking a balance between her needs and those of others can be very difficult, and may lead to guilt when she cannot meet the expectations of those around her. This guilt, in turn, can become an obstacle that prevents her from taking proper care of herself. Further, Romero et al. conclude that, “a self-sacrificing posture develops that may predispose her not only to feeling resentful, but to a variety of health problems as well” (Romero 2000:232). One of these health problems is preterm labor.

Stress

In 2008 Hobel et al. published a thorough review of the state of research in disparities in prematurity and birth outcomes. Psychosocial stress was identified as a major area of focus for current research efforts, and risk perception is a component of psychosocial stress. “More often than not, the number or type of life events emerges as a less important predictor of preterm birth than how stressful, negative, or aversive the experiences were perceived to be” (Hobel 2008:335). The authors called for a more comprehensive measure than is currently available to address this issue.

Despite the plethora of instruments available for the measurement of psychosocial stress, there is no single instrument that incorporates what we believe to be all of the crucial components needed for adequate screening of maternal stress. It is our opinion that development of such an all-encompassing screening tool would be of considerable benefit to clinicians. [Hobel 2008:338]

Maternal perceptions play a critically important role in how their bodies respond to stressors, and in turn, how their pregnancy outcomes are affected. Including the family is an important aspect in this research on risk perception, as it, too, may impact pregnancy outcome. An example of the role the family can play is from the research by Feldman et al. (2000) who found a positive correlation between the amount of social support a woman received during pregnancy, and the birth weight of her baby.

Gender studies in psychology have shown that women are more likely to respond to mistreatment by “acting in” or internalizing their hurt, while men are more likely to “act out” or externalize their response (Myers 1995; Rosenfield 1980). For African American women this is particularly true, despite the contrasting, stereotypical media portrayals of them as loud talking and aggressive. In a study examining the relationships between hypertension and discrimination, Krieger (1990) found that black women who experienced and quietly accepted unfair treatment were four times as likely to have high blood pressure as those who took action in response to the treatment.

In addition, the black women were six times more likely than white women to respond passively to unfair treatment. The implications for these types of responses are discussed by Dole et al. (2004), who found in a study of psychosocial factors that affect preterm birth in black and white women in North Carolina, that there was a slight increase in preterm delivery among black women who reported having experienced racial discrimination. They also found a modestly increased risk of preterm delivery in the black women who reported their coping style involved distancing from problems.

Janet Rich-Edwards et al. (2001) explained how chronic psychological stress is implicated in preterm delivery. Placental corticotropin-releasing hormone CRH, dubbed

the molecule of adversity, is the first hormone in the cascade of hypothalamic-pituitary-adrenal (HPA) stress response. It is produced in large amounts by the placenta, and the level rises rapidly to mature the fetal lung when the time for delivery approaches. In the case of preterm labor, the level of CRH can also be found to have risen significantly. It is therefore theorized that “maternal psychological stress may precipitate surges in neuroendocrine stress responses that simulate placental CRH production . . . to hasten delivery from a stressed environment” (Rich-Edwards et al. 2001). The authors further suggest that a stressed host environment may well exist long before conception. Rich-Edwards et al. (2001) hypothesize that there is a long-term response to a chronic threat. There is such a demand on the system’s ability to respond to stress, that it becomes overloaded and loses its ability to achieve homeostasis, weakening her cardiac, metabolic and immune systems.

Another similar concept is that of the “weathering response.” Geronimus (1992) observed that the risk of delivery preterm increased rapidly with advancing age among African American, but not white women, in Michigan. She believed that the more “weathered” a woman became in her exposure to racism and discrimination the more likely she was to deliver preterm. Simply put, the older the woman was, the longer she had been exposed to the deleterious effects of a climate of racism. There are no commercial products on the market that serve as a sealant or protectant against racism. The only protection comes from within, from the cultural forms that are learned from infancy to shield against these external insults. However, the manner in which African American women view and adapt to stressful living conditions can negatively impact pregnancy outcome.

Thomas (1998) suggests that by broadening the scope of adaptive theory to acknowledge social and political realities, insights can be gained as to “why so many people suffer the consequences of stress despite their best efforts to adapt to environmental conditions.” Psychosocial stress, which encompasses acts perceived as threatening, can lead to an endocrine response of alarm and resistance. Normally this response is short lived, because the threat is short lived. If however, there is the perception of sustained or repeated threat, chronic activation of the stress response can lead to such conditions as cardiovascular disease, ulcers, hypertension, and immune suppression. For many, racism presents as both a sustained and repeated stress, and, as with the observation made by Geronimus, the longer the exposure, the greater the damage. However, the biological explanation for this health impact is incomplete.

Stress in Pregnancy

“Researchers must address the possibility that the same aspects of stress may not pose a risk for preterm birth in the same manner for all racial and ethnic groups” (Behrman and Butler 2007). Stress, and its impact on pregnancy, has received increasing attention in research, with numerous investigations representing biomedical and social science disciplines. Stress, as a factor in the onset of preterm labor, is biologically plausible. It is known, as stated above, to cause the release of catecholamines and cortisol, and could, “prematurely activate the placental corticotrophin-releasing hormone, thereby precipitating the biological cascade leading to preterm labor” (Behrman and Butler 2007:110).

Giscombé and Lobel (2005) published an extensive review of the factors associated with preterm birth, building a strong case for stress, particularly racism-

related stress, as the factor that explains the enduring disparity in birth outcomes. In this work, the authors discussed the high rate of infant mortality among African Americans, when compared to European Americans, and the disparate rate of preterm births between these two groups, despite controlling for income, age, parity, education, health behaviors, and health insurance coverage.

It is important to acknowledge, at this point, that pregnancy, in general, can be stressful for any woman. Pregnancy can affect employment, income, family relationships, housing needs and social roles. It is also physically challenging as the woman's body undergoes tremendous physiological changes in a very short period of time. How this is experienced is affected by whether this is an intended or unintended pregnancy, the mother's age, her occupational status, her socioeconomic resources, previous pregnancy history, and her current state of health (Lobel 1998).

Prenatal stress has been shown repeatedly, in a wide array of multivariate studies, to be associated with low birth weight and preterm birth (Dunkel-Schetter and Lobel 1998). Historically, most of these studies have been conducted with white women, but those studying African American women have confirmed that stress is a risk factor for preterm birth. The specific stressors may vary by ethnicity, and studies using various scales to measure stress have at times yielded equivocal results, based on how the individual perceives life events. As mentioned earlier, this differential in how stress was associated with birth outcomes between black and white women was discussed by Oths (2001) who found job strain to have a significantly greater impact on blacks, and Buka (2003) who found neighborhood disadvantage only had an impact on blacks. Collins et al. (1998) also showed that that very low birth weight (VLBW) was associated

with African American women experiencing chronic stress from their perceptions of living in disadvantaged neighborhoods.

There are several theories that can explain why African American women are more susceptible to certain stressors. The first is related to allostasis, or the body's ability to maintain homeostasis by fluctuating the body's physiological systems to meet demands from external forces. When challenged with frequent or chronic stress there is an excessive demand on the body's regulatory system, and the allostatic load increases (McEwen 1998). Elevated allostatic load or reduced allostasis, has been shown, by measuring cardiovascular and other physiological functions, to predict "mortality, incidence of cardiovascular disease, and decline in cognitive and physical functioning" (Giscombé and Lobel 2005:666). The allostatic load concept takes into account multiple exposures over time and assesses cumulative risk and its impact on multiple physiological systems.

The accelerated build up in the allostatic load in African Americans is related to chronic exposure to racism, both seen and unseen, recognized and unrecognized, in this society. The three forms of racism described earlier (Jones 2000)—institutionalized, personally mediated, and internalized—and two other forms, cultural and collective (Utsey and Ponterotto 1996), all impact the lives of black people in the United States.

A brief review of these forms is presented here as a preface to the impact of racism-related stress on pregnancy. Institutional racism comprises the societal structures that prevent equal access to housing, which in turn results in poor access to good schools and education, which leads to poor employment opportunities, poor

access to health care, and detrimental environmental exposures. It also is apparent in the criminal justice system (Chideya 2000), in which African Americans, who comprise 13 percent of the total U.S. population and are approximately 15 percent of those who use drugs, comprise 35 percent of those who are arrested for drug crimes, and 50 percent of those who are convicted for these crimes (Giscombé and Lobel 2005:667).

Personally mediated racism, that which occurs with direct, personal experience with a racist act, and internalized racism, or acceptance of a devalued sense of self worth, are the two other forms presented by Jones (2000). Utsey and Ponterotto (1996) characterize “cultural racism” as the case in which the cultural norms, practices and values of one group are considered superior to another. They describe “collective racism” as the organized attempt to restrict the rights of African Americans, such as in denying them entrance to certain organizations, or participation in certain events.

As is clear from these typologies, racism and discrimination involve stimuli—actions, events, or practices executed by individuals and organizations—that are appraised as stressful and that produce negative emotional responses. Thus, there is a strong basis for conceptualizing racism as a type of stress that can affect pregnant African American women. [Giscombé and Lobel 2005:668]

Not only can high stress levels contribute to unhealthy behaviors, such as smoking, drinking, poor eating habits, and substance abuse, but there are also many physiological reactions that can contribute to the onset of preterm labor. Hypothalamic-pituitary-adrenal (HPA) reactivity is impacted in women suffering from chronic stress which is evidenced by higher adrenocorticotrophic hormone (ACTH) and cortisol levels. Over time, there is an exaggerated HPA reactivity that may reflect, “the inability of a worn out HPA axis for self regulation . . .” (Lu and Halfon 2003:17). This results in

chronically elevated cortisol levels that lead to immune suppression, and raise the allostatic load.

It follows that the allostatic load over the life course should also affect reproductive health. Women who are exposed to chronic and repeated stress may respond to stressors during pregnancy with higher output of norepinephrine and cortisol, which could increase CRH gene expression leading to preterm labor. Higher levels of glucocorticoids can lead to relative immune suppression, which could increase the likelihood of chronic colonizing of pathogens in the genital tract at conception and during early pregnancy. [Lu and Halfon 2003:17]

The steps in this physiological reaction to stress include (1) the neuroendocrine pathway whereby CRH activity leads to the overproduction of cortisol in a stressed environment; (2) changes in the cardiovascular system that can result in elevated blood pressure in the mother and lower birth weight infants; and (3) a suppressed immune system that leads to a higher incidence of the urogenital infections implicated in preterm labor and premature rupture of membranes. Jennifer Culhane et al. (2001) demonstrated that the assessed risk factor most highly associated with bacterial vaginosis was perceived stress.

Research by Klonoff et al. pointed to a distinctiveness in racism-specific stress that evoked physical and psychological symptoms of distress beyond what was caused by general stressors. This was true when controlling for other variables such as age, income and education (Klonoff et al. 1999). Klonoff and Landrine (1999) also found that 98 percent of African Americans reported experiencing some type of racism in their lifetime, 96 percent had experienced racial discrimination in the past year, and that 95 percent considered the experience of racism to be stressful. Giscombé and Lobel (2005), in addressing the research evidence on the distinct relationship of racism-specific stress to prematurity stated the following:

...it suggests that studies that have failed to assess racism in pregnant African American women may have underestimated their stress, and thereby overlooked an important factor to help explain ethnic disparities in adverse birth outcomes. [Giscombé and Lobel 2005:668]

Nuru-Jeter et al. (2008) offered a discussion of how the stress of racism can affect birth outcomes. In their article, “The Skin You’re In: African American Women Talk About Their Experiences of Racism,” they described the results of their exploratory study to develop measures of racism for birth outcome studies. By conducting a series of focus groups with a total of 40 African American women over age 19, who had children ages 15 and under, they identified six ways in which these women experienced racism. The participants were socioeconomically diverse, with varying levels of education. These women reported experiencing racism:

- 1) Throughout the life course, with childhood experiences seeming particularly salient and having especially enduring effects
- 2) Directly and vicariously, particularly in relation to their children
- 3) In interpersonal, institutional, and internalized forms
- 4) Across different life domains
- 5) With active and passive responses
- 6) With pervasive vigilance, anticipating threats to themselves and their children. [Nuru-Jeter et al. 2008:29]

The biological plausibility of racism impacting birth outcomes is suggested as being through stress-related physiological pathways. While racism is generally viewed in research as a psychosocial stressor, it is multidimensional. As a construct, its components, according to Lazarus and Folkman (1984), begin with the initial exposure to a stressor, and then the manner in which the threat is appraised cognitively,

emotionally, and behaviorally (Nuru-Jeter et al. 2008:30). The physiological response to that appraisal can have long term effects. Nuru-Jeter et al., in referring to the allostatic load, stated, “over time, adaptational responses to stressors, especially chronic or severe stressors, may produce physiologic wear and tear, or allostatic load, which can erode the body’s ability to regulate key biological systems, thereby increasing susceptibility” (Nuru-Jeter et al. 2008:30). Also, in keeping with the “weathering” concept referenced earlier, Geronimus (2006) showed where the higher allostatic load patterns of African American women, when compared to white women, was implicated in accelerated reproductive aging. She found in her research that the odds increased three-fold for low birth weight infants (less than 2500 grams), and four-fold for very low birth weight (less than 1500 grams) infants among African American women with increasing age, but this did not occur among white women (Geronimus 1996). This would mean that the cumulative effect of the allostatic load on their reproductive health is manifested in increasing rates of preterm birth.

Several important factors are shared by the authors that build the case for racism having an impact on preterm birth. First, Harrell et al. (2003) demonstrated in the laboratory setting that African Americans show an increase in reactivity in response to racist stimuli. Second, low risk pregnant women with increased blood pressure reactivity to laboratory stimuli have had shorter gestation lengths and lower birth weights (McCubbin 1996). This association between blood pressure reactivity and birth outcomes is significant because African American women are the ethnic/racial group with the highest rate of hypertensive disorders in this country (Samadi et al. 1998). Third, preterm labor, premature rupture of membranes, and preterm birth have all been

associated with bacterial vaginosis, a lower urogenital tract infection (Goldenberg et al. 1996; Romero et al. 1998). This high incidence of bacterial vaginosis in African American women was the condition found by Culhane et al. (2001) to be linked to chronic maternal stress.

The women in the focus groups talked about racism over the life course, and pointed to early experiences of racism, particularly in childhood, as having the most distressing effect on their lives. They discussed the frustration of day to day experiences with racism, such as in the workplace, while shopping, and while transacting business, and how their reactions varied from active to passive. The impact of these experiences was manifested behaviorally, emotionally, cognitively, and somatically (Nuru-Jeter et al. 2008:34). The other area of profound concern was for their children and the negative experiences of racism their children endured. They described a “pervasive sense of vigilance in anticipation of future racism events for themselves and their children” (Nuru-Jeter et al. 2008:34) that acted as a chronic stressor.

The study by Nuru-Jeter et al. elucidated how African American women of childbearing age described and experienced racism, and the authors concluded, “More comprehensive racism measures may enhance our understanding of the association between racism and birth outcomes and guide work to elucidate specific psychophysiological pathways through which racism experiences adversely affect pregnancy outcomes” (Nuru-Jeter et al. 2008:36). Adding to the discussion of the association between racism and prematurity was a study recently conducted in Chicago.

Rankin et al. (2011) examined how African American women's coping behaviors modified the relationship between interpersonal discrimination and preterm birth. By measuring the mothers' perceived exposures to interpersonal racial discrimination, they found that women with both high lifetime and past year exposure to racism in the public setting had a higher percentage of preterm births; however, women who described active coping behaviors for addressing public discrimination were less likely to deliver preterm. Health and coping with discrimination is viewed from the perspective of African American women living in Detroit in a 2004 ethnography.

Sociologists Amy Schulz and Laura Lempert conducted a study in 2004 to "understand health issues as they are defined by African American women living in Detroit neighborhoods" (Schulz and Lempert 2004:442). The authors were exploring how these women defined health and how they saw the communities they lived in as having an impact on their health. Their focus group encounters offered some illuminating insight into the perceptions and lives of these 24 women. According to findings by the Lewis Mumford Center in 2003, "The metropolitan Detroit area is one of the most racially segregated in the country" (Schulz and Lempert 2004:440). Neighborhood characteristics have also been linked to infant mortality (Schulz and Lempert 2004; O'Campo et al. 2007). Through multiple pathways, research suggests that residential segregation based on race may be a "fundamental factor" affecting health (Schulz and Lempert 2004:440)

In their study, three questions were posed to the participants: (1) What does being healthy mean to you? (2) In what ways do your neighborhoods or the things that happen in your neighborhoods affect your health? (3) Thinking about where you live,

what are the things that contribute to good health? Their responses offer critical insight into their shared conditions and their efforts to create health with those conditions.

The women discussed the issue of redlining, that prevented African Americans from obtaining mortgages which comprise wealth and asset accumulation, trying to raise children where there is nothing for them to do, job migration out of urban areas that particularly affected the ability of young people to get entry-level jobs, and erosion of city services that included slow and sometimes no response by emergency personnel (Schulz and Lempert 2004:448). Of particular interest was the observation by the women regarding their “closed door policy.” They lamented that social networking was compromised because women did not want to open their doors for fear of others intruding into their personal lives, and concerns about the ulterior motives of strangers.

Also discussed by Schulz and Lempert (2004) was a term coined by Fine and Weis, (1998:197) “strategic agoraphobia,” or the effort made by mothers to protect their children and families from dangers in their communities by keeping them indoors. They drew a relationship between social connectedness and their individual health statuses. One respondent spoke of her efforts to combat her social isolation by “keeping active” (Schulz and Lempert 2004:453).

They expressed a belief that keeping active helped them to maintain their mental health and avoid the attendant stress and depression that could often accompany their life circumstances. “There is some evidence that active responses to adversity, enacted in response to unyielding structural conditions, may contribute to increased risk of negative health effects” (Schulz and Lempert 2004:458). In discussing this struggle, the authors referenced work by Mullings and Wali (2001) where the “Sojourner Syndrome”,

named after Sojourner Truth, is described as, “African American women’s active efforts to confront overwhelming economic, political, and social challenges” (Schulz and Lempert 2004:458). Profound negative health effects have been reported from working actively against intransigent structural inequalities, such as the conditions of their neighborhoods.

As the historic economic divestment led to racially segregated communities that lacked life sustaining resources in their city, the informants drew a relationship between the structural inequalities and their health. This assessment is supported in research by Williams and Collins (2001) that specifically identifies race-based segregation as a “fundamental determinant of health” (Shultz and Lempert 2004:459).

While the Detroit women interviewed for their study offered a shared perception that the communities in which they lived, and their responsive efforts to address the challenges they faced in their neighborhoods, had a profound impact on their health, no specific reference was made to pregnancy related health concerns. How risk is perceived, given all the life circumstances that create risk for African American women, will be discussed next.

CHAPTER 3

RISK THEORY, RISK PERCEPTION AND PRETERM BIRTH

Risk Theory

Risk theory provides a framework for examining and presenting the experiences and perceptions of women for whom preterm labor and delivery has had an impact on their lives. A brief review of theories of risk will provide a foundation for references throughout this work, and clarify the multiple and divergent manners in which risk has been conceptualized.

In pre-modern times, risk was understood as an act of God. Natural disasters such as storms and floods were thought to be beyond human control, and not the result of bad actions by humans (Ewald 1993:226). During this time, risk was associated with the notion of fate, which was strongly linked to concepts about God (Lupton 2002:320). Notions of risk began to change, however, in the modern era, as knowledge of probabilities and statistics emerged.

Mary Douglas tracks the changes by centuries. During the seventeenth century, in relation to gambling, risk dealt with the probably of an event occurring, good or bad, and the likely magnitude of that event. Next, in the eighteenth century, when marine insurance companies were assessing the chances of a ship making a safe voyage and the probability of the business having a loss or a gain, risk was a neutral proposition. Risk, during this time, referred to the likelihood a given event would, or would not happen. By the nineteenth century, when risk became a central concern in economics, humans were thought to be risk averse. The business owner, for example, would need a clear understanding of the profit incentive in order to decide whether or not to invest in

a venture. The theory was that humans would not knowingly place themselves in a losing position (Douglas 1990:2).

Noting that any process or activity has a probability of success or failure, Douglas explains that probability theory emerged as the calculation of risk, and became “deeply entrenched in science and manufacturing” (Douglas 1990:2). However, as risk rose to the forefront of the political arena, it moved away from neutral scientific fact. Douglas explains that “*risk* now means danger, and *high risk* means lots of danger” (Douglas 1990:3). Whereas high risk was once a notion of probability of whether a throw of the die would bring great joy or great sorrow, “*risk* now only refers to negative outcomes” (Douglas 1990:3).

Epistemological Positions on Risk

Deborah Lupton (1999a) presents three primary epistemological approaches to risk: realist, strong constructionist and weak constructionist. The *realist* position encompasses the techno-science and cognitive science perspectives. The cognitive science perspective says that there is, in nature, a risk that can be scientifically calculated, and that there is a linear relationship between the knowledge of a risk, developing an attitude that one is at risk, and then adopting a practice to prevent the risk from happening to oneself. This view assumes that there is, “an objective hazard, threat, or danger that exists and can be measured independently of social and cultural processes, but may be distorted or biased through social and cultural frameworks of understanding” (Lupton 1999a:35).

The *strong constructionist* position covers ‘governmentality’ and post structuralism perspectives. The strong constructionist perspective contends that,

“nothing is a risk in itself—what we understand to be a ‘risk’ (or hazard, threat or danger) is a product of historically, socially, and politically contingent way of seeing” (Lupton 1999a:35). Governmentality, a concept developed by Michel Foucault, examines the government surveillance, discipline, and regulation of populations. Foucault explains how risk discourses constitute new objects, and produce subjects. The question that is answered in this perspective is, “How do discourses and practices around risk operate in the construction of subjectivity and social life?” (Lupton 1999a:35).

Foucault, in his theory of how the state constitutes its subject, characterized the clinical encounter between doctor and patient as “warlike domination,” seeing power relations as fitting with metaphor of war. Medical anthropologist Byron Good disagrees, however, that medical discourse is one-sided. He notes that, “Foucault’s focus on the shaping of the perception—the gaze—by medical discourse and the construction of medical objects through discursive practices. . . denies the role of the subject or the constituting role of consciousness” (Good 1997:69). Recognizing that the body is a source of experience and understanding, Good calls for an understanding of the embodied experience when attempting to learn how medicine constructs its objects (Good 1997:69). So, while Foucault asserts that medical discourses shape their subjects in a unilateral mode (the doctor ‘forms’ the patient), Good counters that the patient is an active agent in shaping that role through his or her own experience and understanding.

The *weak constructionist* position considers risk as, “an objective hazard, threat or danger that is inevitably mediated through social and cultural processes and can

never be known in isolation from these processes. The weak constructionist positions are reflected primarily in the 1) *risk society* or cultural structuralism perspective and 2) the cultural/symbolic or functional structuralism perspective (Lupton 1999a). These two sociocultural theories are examined in the work Beck and Giddens, and the work of Mary Douglas.

Risk Society

Ulrich Beck and Anthony Giddens are best recognized for their development and writings on risk and modernity. During the 1990's they introduced the concept of a *risk society* which reflected the way in which modern society had transformed the view of unanticipated outcomes as being the consequence of human action, instead of nature or fate. Their work examined macro social processes of late modern societies, criticizing outcomes of modernity and civilization and their production of risks such as dire environmental hazards. As a result, "public debates constantly feature discussion of risks and their effects while private lives are dominated by concerns about risk" (Lupton and Tulloch 2002:318).

Risk, in a *risk society*, is linked to reflexivity, accountability, and responsibility. Beck and Giddens observe that, "risk is now viewed as the product of human action and decision making, rather than fate, and is therefore treated as a political rather than a metaphysical phenomenon" (Lupton and Tulloch 2002:318). Their approach relates to the manner in which environmental, industrial and global threats of disaster are interpreted by the individual. With the surge of individualism, "crises are seen as individual problems rather than socially based" (Lupton and Tulloch 2002:318). The question a *risk society* approach would answer is, "what is the relationship of risk to the

structures and processes of late modernity?”(Lupton 1999a:35). The criticism of viewing risk only at the macrosocial level, within a political structure, is that the impact of age, race, gender, nationality and social class is not considered in the evaluation of risk perception. Risk knowledge varies greatly based on these differing identities and cultural subgroups, and is constructed in manners that extend beyond the concerns of threats in the greater society. Social categories play a major role in how risk is constructed, and because of this, cultural theory is well suited as the theoretical framework for this research.

The Cultural Theory of Risk

The *cultural theory of risk* refers to the conceptual framework for examining societal conflict over risk that was introduced by Mary Douglas. The reason cultural theory and the writings of Douglas are suitable as a theoretical framework for analysis is the comprehensive manner in which her theories intersect with the major issues facing African American at risk for preterm delivery. "Culture theory starts by assuming that a culture is a system of persons holding one another mutually accountable" (Douglas 1990:10). Her position is that the organizational structures within a society influence how risk is perceived by individuals within that society, and that culture is key in the construction of risk (Lupton1999a:36).

Douglas sees risk as a socially constructed interpretation. She emphasizes the cultural relativity of judgments about risks, including the differences between groups within the same culture in terms of what is considered as a risk, and how acceptable it is thought to be. According to Douglas, if a person rejects advice about safety or health and is willing to take what seems to be ill-advised risks, this action may not be an

indication of a lack of understanding, but may simply indicate a chosen preference. For the issue is not one of misguided perception but rather is the result of clashes in political, moral and aesthetic judgments on risks (Lupton 1999:38). Importantly, “risk is not only the probability of an event, but also the probable magnitude of its outcome, and everything depends on *the value that is set on that outcome*” (Douglas 1990:10). Emphasis is placed on last the portion of that quote because risk appraisal always carries with it an assessment of how much a given outcome matters to the individual or group. An example may be that a person would be willing to spend twenty dollars playing a slot machine, and willing to accept a loss of that entire amount. That person may feel the expenditure of twenty dollars was worth the entertainment of dropping coins in the machine and watching for the three cherries to line up. However, if twenty dollars was all that person had, and this money was needed for food and transportation that evening, then the perspective used for deciding whether or not to risk the loss would be entirely different. A more complex but more relevant example would be a mother hospitalized for preterm labor symptoms who signs herself out of the hospital against medical advice over concern for her other children. This mother may fear that those caring for her children have unsafe or questionable behaviors, and she prioritizes the wellbeing of her living children over the possible risk of delivering her unborn child preterm.

With the individual self as a risk taker, the individual is conceived as risk averse, because the theory of rational choice “assumes that the individual will always choose according to his [or her] own self interest, and that so choosing is the essence of rational behavior. However, how that interest is conceived or framed is not necessarily

known”(Douglas 1996:102). In the example given above, the mother is making risk assessments and choices based on the perceived risk to her fetus, versus the perceived risk to her living children. Preferences such as these are most clearly explained in cultural theory. The questions that this cultural/symbolic perspective answer are the following. “Why are some dangers selected as risks and others are not? How does risk operate as a symbolic boundary measure? What is the situated context of risk?” (Lupton 1999a:35).

For pregnant women, the question of what is a risk, and the magnitude and value of that risk, is socially constructed. However, it is constructed within the framework of the larger society. Douglas contends that discourses of risk, responsibility and blame become intertwined with biomedical rationality and epidemiology, the result being that individuals are held morally responsible for lifestyle choices that result in disease. In the current political climate in western culture “every death, every accident and every misfortune is chargeable to someone’s account—someone must be found to be blamed” (Lupton 1999a:45).

Douglas conceptualizes a difference between the terms “risk” and “taboo or sin.” In discussing sin and taboo, and the relationship of these concepts to risk, Douglas acknowledges that there is no single norm or culture of risk, but that most cultures moralize and politicize danger. She suggests that in western Christianity, sin is believed to bring about danger to the community, and the public discourse against sin is used in the society to promote moral behavior. The nature of sin is such that it is used to constrain certain activities. Sin predicts trouble, so those tempted to sin fear retribution

from family, friends and others in their social network. “A climate of disapproval grounds the belief that certain deeds are dangerous” (Douglas 1990:6).

She further argues that being at risk is the reciprocal of being ‘in sin.’ When someone is at risk, that person is the one being sinned against, vulnerable, in effect to the sins of others. Conversely, being ‘in sin’ means being the cause of harm. Being at risk, in other words, entails being placed in the role of the victim, threatened by risks imposed upon oneself by other agents, rather than being seen as bringing risk upon oneself through one’s own action (Lupton 1999a:47). “The sin/taboo rhetoric is more often used to uphold the community, vulnerable to the misbehavior of the individual, while the risk rhetoric upholds the individual, vulnerable to the misbehavior of the community” (Douglas 1990:7). Yet, people may sometimes be blamed for being at risk, just as they were once blamed for being in sin. (Lupton 1999a:49). Those who are looked upon with disdain because of their “risky” nature, are sometimes those considered to be the *Other*.

Douglas speaks of how society marginalizes the *Other*, particularly with concepts of pollution, and discusses how notions of risk are used to establish and maintain conceptual boundaries between self and *Other*. “The notion of ‘dirt’ and related notions of ‘pollution,’ ‘contamination,’ and ‘defilement’ are inherently fraught with ideas of risk and danger. These notions spring from cultural concepts concerning boundaries, classifications and categories, the violation of which confounds cultural values and expectations. In this approach, risk may be understood as the cultural response to transgression” (Lupton 1999a:45).

The concept of pollution, as it relates to human behaviors and habits, can be envisioned as those epidemiological risk factors that carry social connotations. Women who use drugs, are sexually promiscuous, are pregnant and unmarried, who have frequent urogenital infections or who have back-to-back pregnancies, can be seen as socially “polluted” by not conforming to society’s standards of behavior. “Ideas about pollution therefore operate at two levels of meaning. At the first level of meaning, which is largely instrumental, pollution ideas reinforce social pressures and rules, uphold moral values, and support political power” (Lupton 1999a:42). In relation to this concept of health risk and an individual’s position in society, “cultural values and social location have always provided the materials for self serving constructions of epidemiological risk” (Rosenberg1988:329). In her book, *Risk and Blame: Essays in Cultural Theory* (1992), Mary Douglas discusses how people explain misfortune and how, in traditional societies, the explanation was moralistic, blaming the victim for her troubles. This process exiated the community from any responsibility (Douglas 1996:5). Although Douglas considers this to no longer be the case, it still applies to the position of African American women at risk for preterm birth.

Minority women, in particular have been marginalized and stigmatized as being “unclean” and not being in conformity with social standards. This stigma, as Douglas states, can be a self-fulfilling prophecy (Douglas 1990:15). “In an individualist culture, the weak are going to carry the blame for what happens to them” (Douglas 1990:16). Risk can be used to marginalize the Other, who is positioned as posing a threat and thus a risk to the integrity of self (Lupton 1999:44). As discussed earlier, in terms of using racial classifications, Douglas contends that society needs to classify people as

part of the human condition, but the consequences of this racist thinking and the objectification of the Other, are serious disparities in health outcomes.

Risk Perception

Current risk theory suggests that in this society, the individual is held responsible for recognizing and mitigating risks, even when the risks come from poverty, unemployment or illness (Lupton 1996; Beck 1992). For many health conditions that plague Americans, there are well identified and prescribed activities to decrease risk. Many forms of heart disease can be prevented by exercise, maintaining an ideal body weight, and keeping cholesterol levels low. Adult onset diabetes can be avoided with proper diet, exercise, and weight reduction. If diabetes does occur, good eating habits, exercise and weight loss become more important, and, proper use of medication, and regular blood sugar testing to maintain a healthy range can all help to delay or prevent serious long term consequences such as kidney failure, limb amputation, and blindness.

Women considering pregnancy are told to do such things as exercise regularly, take folic acid, achieve an ideal body weight, obtain good dental care, quit smoking, and avoid alcohol and caffeine. These instructions are important for the general population, and are expanded for those with known risk factors. Women of reproductive age with chronic medical conditions such as high blood pressure, diabetes, seizure disorders and thyroid problems are counseled to achieve the best possible control of these conditions prior to conception.

What then happens, when the risk comes from a social construct, an ethnic affiliation over which the woman has absolutely no control? How can one mitigate the risk that comes from a social classification conferred at birth? Yet, when all other known

risk factors are controlled for, African Americans still have a rate of preterm birth that far exceeds other ethnic groups in this country.

Despite or perhaps because of the urgency of prematurity as a public health problem, little attention has been paid to the informal, culturally informed understandings of responsibility and harm that are associated with prematurity in the United States. In anthropological studies of other medical conditions such as diabetes (Hunt 2001) infertility (Becker 1994), cancer (Hunt 1998; Frank 1995), heart disease (Good 1997) and others, the impact of a non-normative health outcomes is associated with cultural meanings, interpretations, beliefs and values, and these inform health practices.

In negotiating the complex discourses of blame, stigma, and responsibility, there is a conflict on one hand, between identifying groups that are at risk, and on the other, identifying individuals to target for risk reduction by focusing on individual risk management. An analogy can be drawn to issues that have arisen in HIV risk prevention. In an article examining HIV prevention programs in Poland, medical anthropologist Jill Owczarzak (2009) makes several observations that are relevant to the concerns of African American women who are at risk for preterm delivery.

First, in HIV education programs, a common model is to teach the public what behaviors are known to be risky, with the assumption that knowledge alone of the objective risks of transmission constitutes prevention (Owczarzak 2009). Yet, for the woman faced with the possibility of a second preterm delivery, there are often no risk behaviors for her to avoid. Women who have been through this experience frequently are not involved with deleterious behaviors most commonly associated with an

increased risk for preterm birth. Where, then, does the risk arise? Or, more importantly, where does the pregnant women believe it originates?

Second, an individual's agency is subject to evaluation based on that person's ability to assess, manage and avoid risk (Owczarzak 2009:402). How does the woman at risk for preterm delivery assess, manage and avoid risk in light of the fact that there is no blueprint for active risk reduction? How is her agency manifested?

Third, Owczarzak (2009) tells of how harm reduction strategies are aimed at fixing the individual, instead of the social context of the life of the individual that is responsible for shaping that risk. This issue of focusing on the individual, rather than the larger society, was also raised by Juliet McMullin in her book, *The Healthy Ancestor*, which addresses the indigenous health concerns of the Hawaiian people. A popular concept is that the health of native Hawaiians is poor due to a failure to seek care, non-compliance, and some inherited lack of immunity. McMullin suggests that this approach masks social inequalities and shifts blame. "Health inequalities are often characterized as outcomes of individuals' essential natures rather than an issue of structurally imposed unequal access to resources and spaces that promote health" (McMullin 2009:14).

The *risk society* concept suggests that much of the role of modern society is to identify, calculate, and consequently avoid or minimize risk. Risk reduction is a key part of modernity. However, unlike other risks that can be scientifically calculated and quantified, the challenge of risk assessment for a given pregnancy is different. "The invisibility of many of the risks as well as their insidious nature cannot be encompassed by traditional conceptions of risk" (Possamai-Inesedy 2006). Possamai-Inesedy

suggests that risk discourses, and medicalization of childbirth create undue anxiety in women for whom actual statistical risk is very low. This author contends that the prevalent use of modern, highly advanced technology in pregnancy increases the perception of risk in all pregnant women, regardless of their actual risk status.

There is an uncertainty of pregnancy outcome all women, particularly those labeled as “high risk.” Further, this label of *risk*, as Mary Douglas (1992) points out, is not a neutral term, but carries with it only a negative connotation. Lupton (1999b) argues that the pregnant woman suffers from a doubling of risk, and a doubling of responsibility, because an untoward outcome is primarily blamed on the mother, either from the medical community, the family, and/or the larger society. The designation of being at risk, and the subsequent poor pregnancy outcome, takes a tremendous toll not only on the mother but her family as well. It is not an event that is experienced in a vacuum, but one that has far reaching implications. Understanding how this risk is perceived is a missing component in prematurity research.

A few studies to date have addressed the issue of risk perception in pregnant women, but none have focused on the African American population, their families or providers. In 2006, in the *Western Journal of Nursing Research*, Bobbe Gray published the article, “Hospitalization History and Difference in Self-Rated Pregnancy Risk.” Her finding was that women who were interviewed after their release from the hospital had a higher perception of risk for both themselves and their infants, than either the group of pregnant women who had never been hospitalized or the group that was currently hospitalized. Ethnicity was not reported in Gray’s study, however, data from that research helps to inform a research design that includes the hospitalized patient.

In a design similar to the one proposed for this research, Coffman et al. conducted a research study that was published in *JOGNN* in 2006. Interviews were conducted with African American women with high risk pregnancies both in the hospital and in the participants' homes. The study was designed to elicit information about social support, and concluded that this support was a mutual transaction that involved intentionality (Coffman et al. 2006). Family relationships were a key component. The results of this study validate the importance of including family members in the investigation of this phenomenon.

Risk Perception and Preterm Birth

Four studies over the past two decades have addressed the issue of perception of risk among pregnant women in a manner that is consonant with this research. A brief description of these studies will be presented here, and the relationship of their findings to the findings of this research study will be reviewed in the discussion section of this paper.

In an institutional, ethnographic study by Canadian nurses (MacKinnon and McIntyre 2006), the authors sought to answer three questions: (1) How do pregnant women experience preterm labor? (2) How do women who experience preterm labor describe their everyday work in caring for themselves, their unborn babies, and their families? (3) How are the experiences of these women affected by societal discourses, institutional structures, and nursing work processes (Mackinnon and McIntyre 2006:62). The eight women who participated in the audio-taped interviews had all experienced preterm labor symptoms, and four of those had delivered preterm infants. Eighteen

nurses working in the obstetrical triage unit and antepartum units of three hospitals in western Canada were also interviewed (Mackinnon and McIntyre 2006:64).

The authors point out that risk, when used as a technical term in obstetrics, represents the probability of a poor outcome (Mackinnon and McIntyre 2006:58). The biomedical concept of risk constructs it as something that is measurable, predictable and manageable (Mackinnon and McIntyre 2006:58). However, the diagnosis of preterm labor is often ambiguous, and the most common intervention, bedrest, has not been shown to decrease the risk of preterm delivery (Goldenberg and Rouse 1998). Further, women who do not comply with biomedical prescriptives are deemed to be a risk to their unborn babies. Women at odds with the medical advice are often viewed in the biomedical arena as non-compliant, but, according to Douglas, this assignment of risk is not so much an indication of a level of real danger, but how that danger is politicized. (Mackinnon and McIntyre 2006:59).

An observation by the writers was that, although biomedical discourses appeared to be neutral, they found in their analysis that the discourses actually functioned to maintain power relations. “These objectifying discourses and practices displaced local knowledge about the needs of women and families” (Mackinnon and McIntyre 2006:69). They emphasized that there was a “disjuncture between women’s everyday experiences and the need to comply with medical regimens that frequently included bedrest” (Mackinnon and McIntyre 2006:69). Despite the biomedical construction of risk within the health care facility, economic considerations required that women be sent home, and this is where economic and social discourses intersected to locate the responsibility within the private residence. The problem with this relocating of

responsibility from the public institution to the private home was the assumption that the family would be responsible for the care. This assumption was made without an assessment of resources within the home to carry out the medical plan or an offer of resources to families to do so (Mackinnon and McIntyre 2006:69). The women in this study often expressed a profound sense of responsibility to prevent a preterm birth, and some women believed they failed in the work of “keeping the baby in” (Mackinnon and McIntyre 2006:65).

A second study that bears examining, “Women’s Experiences of Preterm Labor: A Feminist Critique,” by Susan Chamberlin Williams and Marlene Mackey (1999), is one that utilizes a feminist approach. In examining the accounts of 29 women with preterm labor (PTL) the stated objectives were “(1) to show that the medical explanation of PTL is widely accepted, yet is only a singular version of the truth; (2) to demonstrate how the PTL landscape changes when consideration of women’s lives and understandings are added to dominant medical practice; and (3) to suggest that the PTL experience is profoundly affected by issues of race, class and gender” (Williams and Mackey 1999:30).

An explanation for using the feminist approach is that “feminist thought sees its task as not promoting the needs and experiences of women as normative or universal but as making visible the varying experiences and perspectives that masculinist thought denies” (Kaschak 1992:11). The authors’ goal was to “explicate how women’s experiences both compare and contrast to dominant medical theory and to other competing viewpoints as expressed in scientific and scholarly literature” (Williams and Mackey 1999:31).

The feminist interpretation of women's PTL experiences within the mainstream culture of American obstetrical practice was a focus of this research, and a theoretical emphasis was placed on the objectification of women, the medicalization of women's lives and the manner in which women experience a loss of control, as the reproductive experience is controlled by physicians and medical intervention (Williams and Mackey 1999:31). Not only can this experience be interpreted through a feminist analysis, but also through Foucault's discussion of how medical discourse creates subjects.

"The narratives of the women who experienced PTL indicated that what happened to their bodies was influenced as much by the particular circumstances in their lives—and the woman's response to these circumstances—as it was by medical risk" (Williams and Mackey 1999:36). Relative to the framework of cultural theory, is the societal role accepted by women that reinforces a sense of having committed some social wrong. "One explanation for the willingness to accept blame is the tendency toward self-punishment, in a culture where women are assumed to drive the car in which the fetus is merely a passenger" (Williams and Mackey 1999:34).

Lisa Handwerker (1994) examined medical risk as it pertained to poor pregnant women. Acknowledging that risk analysis would ideally offer the ability to predict events and eliminate uncertainty, she notes that, "we cannot adequately deal with the ambiguities of people's lives in merely quantitative terms" (Handwerker 1994:666). Commenting that risk literature views science as unproblematic, it blinds criticism to the fundamental issues of risk significance, and the fact that risk meanings differ for epidemiologists, clinicians and patients. In reality, risk assessment is highly subjective. Her focus in this article was on how poor women were treated in the health care system,

from having to spend long hours awaiting exams in public clinics, to being stigmatized with the label of high risk (particularly black women). She also problematized a common practice of clinicians to assess the health of the fetus as a separate entity from the mother, disregarding the mother-fetus relationship (Handwerker 1994:668).

“Patients’ understanding of risk often differs from that of medical professionals and depends on their values, education, class, and other markers affecting their location in the social structure” (Handwerker 1994:669). There is a subjective experience to risk that is often overlooked in the health care setting, and lived risk can differ from statistical calculations. As Gupton et al. agree, pregnant women do not use objective statistics to assess risk; their subjective perception of risk is based on their own available heuristics and issues such as controllability, familiarity, immediacy of consequences and the ease of reducing risk all factor into these assessments (Gupton et al. 2006:194). Or, simply put, women make decisions based on their perceptions of what constitutes risk, within the framework of the social, political and economic realities of their lives (Handwerker 1994:671). It is their location within society, as Douglas suggests, that impacts their perception.

A fourth study, closely aligned with these investigations of perception of risk, was conducted by nurse researchers in 2000, investigating explanatory models of preterm labor among 14 pregnant women diagnosed with preterm labor (PTL). The authors explained, “an explanatory model tells us how individuals conceptualize an illness in terms of its causation, how individuals who are ill should behave, and what action they should take in response to illness” (Mackey and Boyle 2000:256).

The explanatory model generated in the study was described as a “social construction of how women described what they believed caused PTL, and how they attempted to alleviate it” (Mackey and Boyle 2000:256). This study, as well as the previous ones described, can be analyzed within the cultural theory framework of Douglas. “Culture helps us create meaning out of illness, and make sense out of life events” (Mackey and Boyle 2000:256).

All of the women interviewed identified stress and a major factor in their preterm labor symptoms, and stress was often defined as “overdoing it” (Mackey and Boyle 2000:257). The authors discussed, at length, the conflict these women encountered over their gender specific cultural roles as wife, mother and homemaker, and how they demonstrated their love and support for their families through these roles. Not being able to fulfill these cultural and societal expectations for their traditional roles was stressful and led to tension among family members. Pregnancy actually served to compound difficult home life situations where there were constant family demands. Notably, the major stressor was the relationship the pregnant women had with their husbands or significant others (Mackey and Boyle 2000:257).

Prescriptions for strict bedrest were a serious source of difficulty, and the ability to maintain bedrest rested heavily on the women’s support systems. Their success in following doctors’ orders “centered on the participants’ ability to elicit help from others, maintain support, adhere to bedrest, and block out or ignore those situations or factors that caused stress before the onset of PTL” (Mackey and Boyle 2000:259). The mothers of the pregnant women were the key sources of support, and several of the informants indicated that the relationships with their mothers were strengthened, and at

times repaired, as at result of their PTL experience. Several findings and recommendations emerged from their study. First, women clearly identified stress as the explanatory model for PTL, and those who were able to mobilize support and decrease their activities were subsequently able to decrease the stress in their lives. Next, because the need for support is so critical, women experiencing preterm labor may need guidance and encouragement from health care providers in order to seek that support from others. Third, assessment for PTL risk should extend beyond physiological measures. Finally, involving family members in the interventions for PTL can be cost effective, and helps clients by decreasing stress.

These four studies, though employing different theoretical approaches, offered similarities in findings for women at risk for preterm birth. Most importantly, the studies highlighted the absence of substantial research specifically designed to elucidate the explanatory models of African American women, their families, and their health care providers.

CHAPTER 4

CROSS CULTURAL PERSPECTIVES ON RISK

While cross cultural studies on pregnancy and child birth practices are abundant in medical anthropology research (Rapp 2000; Martin 2001; Clark and Olesen 1999; Davis-Floyd 1994, 2003; Jordan 1993), there is a paucity of qualitative information on the perceptions of risk for preterm birth across cultures. A cross cultural examination of research published through the National Institute of Health, the World Health Organization (WHO), the Human Relations Area File (HRAF) and 30 years of Annual Reviews in Anthropology yielded only modest insight into how prematurity and its causes are viewed among women and their communities in locations throughout the world. Several studies, however, address risk in manners that have relevance to this discussion.

In a study conducted with Icelandic nurse midwives by a masters nursing student, (Sigurðardóttir 2008) the author observed, and lamented, that midwives working in major medical institutions were beginning to alter their historical, philosophical stance of viewing pregnancy and childbirth as normal physiological processes, and were adopting the dominant biomedical model position, viewing these processes as risky and fraught with hazard. The result of these shifts in ideology was that the midwives were becoming increasingly less dependent on their clinical skills of assessment and were depending on technology to inform their care giving practices and interventions. As the nurse midwives began to embrace the use of technology designed to detect danger, their patients consequently constructed their childbirth expectations with greater apprehension. The midwives, working in high risk intervention units,

believed that they were being impacted by “contamination from the environment” (Sigurðardóttir 2008:93), and were accepting technological interventions as “normal.” The midwives experienced a change in risk perception and started to view labor and childbirth as inherently risky, instead of inherently safe. The conclusion of this article was that midwives needed to return to their basic belief that physiological childbirth was both normal and ideal, and that they needed to convey this to the patients in their care to relieve their anxiety over danger, and enhance their sense of safety. Risk perception was heightened in the face of advanced technological monitoring and intervention, and lessened with the promotion of physiological birth. Her study, while not addressing preterm birth, highlighted the manner in which risk perception can be altered through biomedical discourses.

In 2005, Badr et al. compared preterm birth in groups from the Middle East and the United States. Women in Egypt, Lebanon, and California were interviewed in the hospital, postpartum, to identify factors that contribute to preterm birth. The women from the United States were Mexican American and white American. The factors significantly related to preterm birth for the Middle Eastern women were less exercise, greater stress (from marital discord and domestic violence) and lack of support/help from family and friends. For the American women, the significant predictors were less exercise, less support/help from family, smoking, and greater stress (Badr et al. 2005:448). For all four groups, social support, stress/domestic violence and exercise were the three common predictors. “It appears that the stress experienced during pregnancy, as well as poor support for the mother, may be the two strongest predictors of preterm birth, irrespective of ethnicity, culture, poverty, or other factors that may

influence preterm birth” (Badr et al. 2005:449). While the authors concluded that these factors may be universal predictors of preterm birth, regardless of nationality or any other individual risk factors, the study did not address the personal perceptions of the women interviewed. Perception of risk, however, was investigated in the next study.

In a study conducted in Shivgarh Block in Uttar Pradesh, India, where 88 percent of births occurred at home, recently delivered women, their families and health practitioners (midwives, unqualified village doctors, and traditional healers) were interviewed to understand how birth weight was perceived in a low resource setting (Darmstadt et al. 2008). What was found was that there were different criteria used to judge the health of newborns, including feeding, vigor or weakness, overall appearance of health, and alertness. The community, however, did not consider weight as a significant factor in newborn health, and so this was not offered as part of the discussion by informants. Conversely, they were concerned about pregnant women eating too much, because they feared the fetus would grow too large, resulting in a difficult birth. While this study was not designed to determine the perception of the sources of risk for preterm birth, data from the interviews did reveal beliefs as to why infants were born unhealthy. For problems observed in the infants such as weakness, paleness, fragility, shrunken eyes and difficulty breathing, the causes were invariably the result of some bad act by the mother. She may have overeaten, failed to properly space her pregnancies, been sedentary after delivery, fed her baby immediately after sexual intercourse or had a poor postpartum diet (Darmstadt et al. 2008:s56). Community members described in detail their reasoning and the circumstances under which they would seek medical treatment for an ill infant. The explanatory models for the causes of

illness that were shared by the respondents were valuable in assisting health care workers to plan interventions to improve the survival of low birth weight infants. However, the causes of prematurity were never related to the larger social, economic and environmental conditions facing the residents of Shivgarh. The consistent explanation for the causes of risk, and poor outcomes, were the actions of the mother.

Sue Kildea (2006) discussed birth dynamics in Australia, where Aboriginal authoritative knowledge and customs were often disregarded because of the assumption by clinicians that the western model was the “best”. Many rural medical facilities were closed, so Aboriginal and Torres Strait Islander women had to travel long distances to give birth in facilities where they were totally separated from their families, communities and culture. To the Aboriginal women, giving birth without the proper cultural setting, practices, and supportive community was a higher risk factor than the narrow focus on safety. Their actions were reminiscent of Foucault’s assertion, “where there is power, there is resistance (Foucault 1978:95-96) and Byron Good’s analysis that, “for medical anthropologists, the term resistance has served to bring attention to cultural forms and activities which resist the medicalization of our lives and the thus the encroachment of hegemonic cultural forms” (Good 1997:58).

This risk perception by the indigenous women was supported by impressive statistics cited about an indigenous population in Canada. The Inuit people regained control of their birthing processes, making them culturally correct, with a resulting drop in infant mortality from 8.6 percent to 3.6 percent. They also had a 50 percent decrease in inductions, and a rate of caesarean section birth of 2.4 percent, compared to 26.8 percent in Quebec (Kildea 2006).

Just as the western model of health care did not yield the best outcomes for the Inuit women, the same was true for Australia's Aboriginal women. The implementation of the western model did not result in a significant improvement in birth statistics. Preterm labor was not specifically addressed in these discussions but the agency the women demonstrated in laying aside the authoritative knowledge risk discourses, offered a clear example of how the biomedical construction of risk is only one of several discourses to be considered.

Preterm births occur throughout the world, and are a major focus of epidemiological attention internationally because of the impact on infant mortality and morbidity. However, an extensive review failed to identify significant qualitative investigations outside of the United States on culturally constructed perceptions of risk and how these perceptions impact behavior. What is evident from these studies is that women often carry the burden of blame for untoward birth outcomes, that authoritative knowledge and biomedical discourses on risk impact risk perception, and that maternal stress may impact the rate of preterm birth in multiple locations throughout the world.

CHAPTER 5

METHODOLOGY

Research Questions

How do African American women, identified as being “high risk” for a second preterm birth, understand and construct the nature of their risk, and how does this understanding impact their families, their prenatal beliefs, their behavior, self-evaluation and self-care? How do key others involved in the wellbeing of the mother and fetus—the woman’s mother, the father of her unborn child, physicians, nurses and medical assistants—understand the woman’s risk? What is the individual woman’s understanding of this condition and her interpretation of her own risk for a second preterm delivery? Specifically, explanatory models will be constructed through investigation into the following:

1. How is the designation of risk perceived by the families of these women, and how does it impact social relations?
2. In terms of causality, how do patients, their families and practitioners assign responsibility, explain what has happened, and explain why it is happening? How does race, racism and inequality factor into this discussion?
3. How is the rational clinical discourse concerning risk assessment through probability and statistics embodied, interpreted and expressed in the individual women at risk?
4. Examined through the lens of the women’s experience and agency, how does their knowledge that they have a three-fold increase in the risk of having another preterm birth affect their lives?

Enrollment Criteria

Those eligible to participate in the study were pregnant African American women (self-identified ethnicity) who had a history of a prior preterm delivery, and who were hospitalized on the high risk antepartum unit of a major urban tertiary care hospital. Excluded from the study were any women who did not self-identify as African American, who had not been residents of the metropolitan Detroit area; who had known fetal abnormalities, major malformations, fetal demise or planned termination; who were currently in labor; who were unable to give informed consent; or who intended to deliver elsewhere. In addition, those whom the hospitalized woman identified as the father of her baby, and her mother were also invited to participate. Finally, doctors, nurses and patient care assistants who cared for high risk women in the medical center were invited to participate in interviews.

Rationale for the Study Design

Being African American alone is a profound risk factor for preterm birth. Few studies to date have focused on people who are conceptualized as a source of risk. From a women's health perspective, and from the perspective of African American health studies, the mother's experience is significant.

Though recognizing from the beginning that the fathers may have been difficult to recruit, it was nonetheless important to include their voices in this investigation. In most investigations regarding pregnancy and childbirth, discussions of the male involved is almost non-existent. Ginsburg and Rapp (1991:328) discuss the "gender-blind or gender-bias" in most research related to pregnancy, childbirth and early infancy, which causes the role or impact of fathers to be disregarded. Although birth outcomes may be

significantly affected by “men’s participation in and influence on prenatal care” (Dudgeon and Inborn 2004:1386), the role of fathers has not been the subject of medical anthropology studies, and is poorly understood. In spite of the fact that, “in the United States, one of the most consistent predictors of adequate prenatal care utilization is mother’s relationship with the father” (Dudgeon and Inborn 2004:1387), fathers are still too often omitted from the investigations of pregnancy-related issues. In this study, fathers are recognized as having the ability to make key contributions to the understanding of risk perception and the construction of risk. In a study by Heaman et al. (1992) of childbirth expectations, comparing high and low risk women, a conclusion of the study was that the inclusion of partners of high risk women was important in preparation for the birth (Heaman et al. 1992). Husbands and partners not only provide needed support, but they also have opinions, viewpoints and perspectives that can that can powerfully influence the pregnant women, and should be taken into consideration in any study of pregnancy-related issues.

Additionally, physicians, nurses and medical assistants add breadth and depth to this discussion, and help to identify differing locations of risk. The inclusion of health care providers offers additional explanatory models for this complex condition of risk, and for the sources of responsibility for factors that put the woman at risk, and impact the outcome of her pregnancy. Also, African American health care providers offer a unique perspective. Deep seated cultural beliefs and values that inform understandings of responsibility, and of sources of threat, color the perceptions and judgments of any cultural actor, even those with specialized technical knowledge, such as the health practitioners who care for pregnant women.

Procedures

The staff of the antepartum high risk unit of Women and Infants Hospital were designated to obtain initial permission from pregnant African American in-patients, who had had a previous preterm delivery, to speak with me. Upon notification, I would meet with the potential candidate to discuss the study and obtain written informed consent. Following informed consent, at a time of the participant's choosing, an initial 45-60 minute face-to-face, audiotaped, semi-structured interview was conducted. This interview, which took place at the participant's bedside, was designed with a mix of closed and open-ended questions. At the completion of this interview, the participant was asked if she would be willing to ask her mother and the father of the baby if they too would like to participate in the study. If the participant and the family members were agreeable, I would proceed with contacting, and making an appointment to consent these two persons. An interview with the individual the pregnant woman identified as her mother, biological or fictive, and the man the participant identified as the father of the baby was then conducted at a time and place agreeable to these individuals. When possible, a second interview was conducted with the pregnant woman, either in the hospital or at her home, within one month of the initial interview. Data was abstracted from the inpatient medical record at the time of the interview to obtain medically diagnosed risk factors, and again after delivery to obtain outcome information.

Data Collection

A total of 11 pregnant women were enrolled. An initial taped interview was conducted for all 11 of these women, at the bedside, in their hospital rooms. The length of these interviews ranged from 45 minutes to an hour. For three of them, a

second recorded interview was conducted in their homes prior to delivery. The subsequent interviews were shorter, and lasted approximately 30 minutes. Six of the 11 women completed the Edinburgh Depression Scale and the Racism and Life Experiences Scale (RaLES).

Two interviews were conducted with the fathers of the unborn babies, and three interviews were conducted with the patients' mothers. Four of these five family-member interviews were conducted in the home, and one was conducted at the mother's place of work. Part of the reason for the small number of family members is the fact that the study was amended to include family members following the fifth interview with a pregnant woman. For the next six women interviewed, two of the baby's fathers were incarcerated, and two declined to be interviewed (by report of the pregnant mom). For these same six women, only three had living mothers, and I interviewed all three of those. Two physicians were enrolled. One of the physician interviews was conducted in his corporate office, and one interview was conducted in the "sleeping room" on the labor and delivery unit. Two nurses were enrolled, one was a certified nurse midwife whom I interviewed in the obstetrical triage unit, and one was a registered nurse whom I interviewed on the antepartum high risk unit. Finally, I enrolled two medical assistants (also known as Patient Care Assistants, or PCA's), both of whom I also interviewed on the antepartum high risk unit. The length of the interviews varied, from 17 minutes with one of the medical assistants, to one hour and five minutes with one of the physicians. The remainder lasted approximately 30 minutes.

My decision to interview one male and one female physician was not for the purpose of obtaining representativeness in my sample, something that certainly was not possible in a sample this small, but to allow for the opportunity to elicit some degree of gender-informed observations through these interviews. The rest of the health care provider informants were female. The reason for this was simple. Not only are nurses and medical assistants overwhelmingly female, but there were no male nurses or medical assistants employed on the hospital unit where the research was being conducted.

Data Analysis

Each of the 25 recorded interviews were transcribed verbatim. The written transcripts were then reviewed for content and thematic analysis for the identification of indigenous themes; explanatory models; evidence of the challenge of expert judgements and authoritative knowledge of risk; the reflexive self-construction of life narratives related to prematurity (concepts of cause and prevention); the relationship between assessment and acceptance of risk and access to material resources; and agency in the reshaping of life trajectories based on culturally informed interventions for risk reduction. Life course experiences, the impact on social relationships, family attitudes, life stressors, and experiences with racism were also explored in the analysis. In particular, the explanatory models of the pregnant women, their families, and the providers were a focus of this investigation. Following review of the transcripts, they were coded and analyzed utilizing the Atlas.ti 6.0 program for qualitative data analysis. Closed or deductive codes were developed prior to the coding, and open or inductive codes were assigned based on the emerging models.

Initial coding was extensive in order to identify both overt and more nuanced references to variables of interest. Codes were then clustered into themes. A listing of the code frequencies is found in Appendix E.

Notes from the Field

My field experiences occurred in two separate arenas. The first setting was the hospital, and second was the home of the participants. In the hospital I was not an outsider, or a stranger in a foreign land, but I was working in an environment that was well known to me, and where I was well known. The second environment, the homes of the participants, also was not strange to me. Being a lifelong Detroit resident, and having had years of professional experience conducting home visits, I felt very “at home” in the residences of the informants.

I began the research by obtaining permission from the nurse manager to present the study at a staff meeting. In order to obtain Institutional Review Board (IRB) approval, I first had to meet with the hospital administrators and the nurse manager on the unit to obtain their written permission to conduct the research, first within the hospital, and second, on the antepartum high risk unit. My meeting with the administrators required that I share in some detail the design of the study, how women would be approached, and what assistance I would require from the nursing staff. I received both approval and very positive feedback about my research goals. I was asked to come back and share my findings once the study was completed. One administrator commented that she was glad that I focusing on the women as human beings, and not just as sources of biological specimens.

My next task was to inform the staff on the unit and elicit their assistance and cooperation to conduct the study. I held three separate meetings, one each with the day shift, afternoon shift and night shift. Although it was not my intention to conduct any interviews on the night shift, I did want all of the staff to be aware of my research, and my request for referrals for participants.

I was very warmly received, but there were very few questions raised in the course of my presentations. Both nurses and PCAs attended the meetings and all stated they would assist. I provided my office number, my pager number, and my cell phone number on a printed summary sheet of the study. I gave one sheet to each attendee, and posted several of the colorfully printed sheets in key locations around the nurses' station. I never received a call.

In order for potential participants to be identified, I had to be present on the unit. Although I initially attempted to do some recruiting during the week, I quickly learned that weekends were far more conducive to my research. In general there was far less activity on the unit, and only core staffing. I would normally come in on a Saturday or Sunday and check in with the unit secretary. There was a large dry-erase board posted on the wall in a section behind the nurses' station that was not visible to the general public. On this board was a grid that listed all the room numbers on the unit. Beside each room number, if the bed was occupied, were the initials of the patient and a row of some basic patient information. Also, each nurse and PCA carried a printed sheet that listed more detailed information about every patient on the unit. This information included the woman's gravidity (total number of pregnancies) and parity (total number or

pregnancies lasting 20 week or greater), gestational age, admitting diagnosis, medications, and monitoring and treatment schedules.

Whenever I arrived on the unit, I would first check in with the unit secretary to let her know I was present, and that I needed to speak with the charge nurse. She would use the intercom system to find the charge nurse, if she was not sure of her present location. I always emphasized that I did not want to interrupt anyone's work, and that I was happy to wait until someone was available. There were only a few nurses who routinely were in charge on the unit, but I would explain each time that I was interested in obtaining permission to speak with any patient who was African American and who had had a previous preterm birth. The charge nurse would review her list briefly and let me know the status of potential candidates. If there was a woman on the unit who met the criteria, I would then speak to the nurse assigned to care for her. I would ask that nurse to speak with her patient, and obtain permission for me to go into the room and talk with patient about the study. Because most of the staff knew me, this raised a small problem. The staff was accustomed to me functioning in my role as a research nurse, where I did not have to first ask a staff nurse to talk with the patient before I could enter the room. The frequent response was, "Oh, Gwen, you don't need me, you can just go on in and talk with her." This was a real temptation, because the nurses were busy, and I knew I could quickly and easily explain the study without having to wait until the nurse got a break. However, I did not yield to the temptation. This was not only because it would be in violation of the IRB approval, but also because I really wanted the patient to understand my role as an anthropologist researcher, as opposed to that of a nurse.

Yet, I see many similarities in my role as a medical anthropologist, and my role as a nurse. Although most writings in anthropology group nurses and physicians together as part of the biomedical model, the field of nursing is often more closely aligned with medical anthropology. Nursing was defined in 1980 as “the diagnosis and treatment of human responses to actual or potential health problems” (American Nurses Association 2010:10).¹ The physician’s role is the diagnosis and treatment of discrete diseases, while nurses focus on the broader components of illness and health. Nurses must be able to work within frameworks of disease or illness, handling situations in which either model may assume primacy. This flexibility makes the nursing role hard to define. Nurses are charged with understanding an illness model that takes into account the cultural, social and psychological circumstances of the lives of their patients. Similar to anthropologists, they are concerned with how patients interpret illness, and the needs that “emerge in response to illness or health states” (Dougherty and Tripp-Reimer 1985: 220). However, for this study, it was important for the patients that I made my role distinct as an anthropologist.

Generally, the patients agreed to talk to me. There was, in fact, only one who refused to allow me to speak with her. Another told her nurse that she did not want to do the research, but it would be okay if I came in the room to speak with her. When I did speak with this young woman, she told me that she was just, “going through too much right now,” and didn’t want to talk to anybody. I told her I understood, and let her

¹*This is the original definition of nursing from the American Nurses Association Social Policy Statement in 1980. Since 2003, the definition has been, “the protection and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals and families” (American Nurses Association 2010:10).*

know that I did, very much, want to have an opportunity to talk with her. I left my contact information in case she changed her mind, but she did not contact me.

Whenever the charge nurse reviewed her list, there was almost always at least one woman hospitalized for preterm issues. However, what excluded these women was the requirement that they have delivered a previous preterm infant. For some, this was their first experience with preterm labor, or a shortened cervix. For others, although they experienced preterm labor with a previous pregnancy, they did not actually deliver preterm.

My challenge, though, with this research, was not the identification of participants. The challenge was to step outside my role as a nurse, to, in essence, remove my “nurse’s cap” and function as an anthropologist. I had had over 25 years experience conducting research with women with high risk pregnancies. I was accustomed to discussing their conditions, answering questions about the current procedures or interventions we were studying, explaining the gaps in knowledge in the medical community, and why it was important to learn more about how to address their medical conditions. In the process of consenting women for these clinical studies, a lot of teaching would take place. It was therefore difficult for me to switch from being the teacher, the one with authoritative knowledge, to being the student. I wanted to answer the questions women asked about their conditions, even though it was not my role to do so.

Instead, my responses had to be changed. I offered responses such as, “I can see that’s a concern for you, did you talk to your doctor about that?” or, “What did your doctor say?” or, “Did you ask your nurse, because she may be able to help with this.”

As a nurse, if a pregnant patient told me of serious issues in her life, I would, of course, and try to make referrals to appropriate resources. In addition, I would try to offer counseling and advice. However, as an anthropologist conducting fieldwork, I had to listen to the stories of lives full of strife and turmoil, and the struggles the women faced, without offering instruction or guidance. While the word “stress” was uttered by each and every informant at some point in the interview, the informants would not always connect their experiences in stressful life circumstances with their health and pregnancy outcomes.

These women, however, all reported that they greatly appreciated the opportunity to share their stories, and have someone listen to them. This was a very positive experience for me, and allowed themes from the discussions of the participants to emerge undirected and encumbered by my input.

CHAPTER 6

THE ETHNOGRAPHIC SETTING: DETROIT, MICHIGAN

Introduction

This ethnography was conducted in the city of Detroit. Detroit is located in Wayne County, in southeastern Michigan. Wayne County has a population of close to 2 million and is the most populous county in the state. It covers an expanse of 623 square miles and is ranked as the 13th most populous county in the nation. It is made up of 34 cities, nine townships, and 41 public school districts. The city of Detroit, which is the county seat, is the largest city in Wayne County. It is the 11th most populous city in the United States and is surrounded by other large communities such as Dearborn, Romulus, Livonia, Taylor, Westland and Canton Township. Wayne County owns and operates two international airports, Detroit Metropolitan Airport, and Willow Run Airport.¹

Wayne County is the historic site of the industrial revolution and the birthplace of the auto industry. It is still home to the world headquarters for Ford and General Motors, but has suffered great economic hardship as result of the loss of automobile factories, jobs (both blue and white collar), and industries affiliated with car manufacturing. Unemployment is very high, particularly in Detroit, which has been hardest hit by the downsizing and outsourcing of the auto industry. However, this is not a problem unique to Wayne County. The state of Michigan currently has one of the highest unemployment rates in the nation.

There are six major health care systems in Wayne County, and within those are two major teaching and research centers. The Detroit Medical Center, the Henry Ford

Health System, the St. John Health System, the Oakwood Health System, William Beaumont Hospitals and the Trinity Health System provide a substantial portion of the inpatient and outpatient care for all Wayne County residents.

The city of Detroit has undergone major changes. Fueled by highway and housing policies that encouraged out-migration, its population decreased from 1.8 million to 951,000 in the period from 1950 to the year 2000. Once African Americans began to purchase homes in historically white neighborhoods and intense efforts to maintain segregated communities were no longer effective, white citizens moved from the city to the surrounding suburbs in massive numbers. This shift resulted in a city that went from 44 percent African American, to 82 percent African American, (though, with very little change in the actual number of black residents). Classically referred to as “white flight,” there was a loss to the city that far exceeded the relocation of some of its residents. As businesses relocated, factories closed, the school system suffered, and the long outlawed practice of insurance redlining persisted, Detroit became a far less attractive place to call home. The tax base eroded both from the loss of business and property taxes, as many people were no longer able to afford to own homes. Severe job loss had a major impact on opportunities for its citizens long before the economic crisis that besieged the country in 2008. It was commonly said that when Michigan caught a cold, Detroit got pneumonia, and with Michigan carrying one of the highest rates of unemployment in the country, the impact on Detroit has been profound. However, historically, Detroit offered great opportunities for its citizens, particularly African Americans.

A Historical Perspective

Over its 300 year history, Detroit, Michigan has variously been named Yondotega (great village), Fort Pontchartrain, Fort Detroit, Arsenal of Democracy, Motor City, Motown, Murder Capital, and the Renaissance City (Gavrilovich and McGraw 2000). During this time Detroit achieved spectacular success in most areas, growing from a small fort on a busy river to a metropolis that showcased the best in urban living. It was a place where African Americans thrived and flourished. In more recent years, however, the city experienced so many serious problems that it is now an example of the many things that can go wrong in urban environments. The factors that led Detroit to become a showcase city, and then those factors that contributed to its downward spiral, are revealed by looking at its history. Additionally, the challenges and conditions of the “Motor City” have created an environment of risk and the perception of risk for the participants in this study.

The auto industry is probably the most visible example of Detroit’s rise and decline. After WWII, half of all the cars in the world were made in Detroit. In 1994 it was about 1 in 1000 (Young and Wheeler 1994:2). In 2011 even trying to determine which cars are “American made” is difficult. The Toyota Camry and Honda Accord are actually the most “American made” cars, having the most American made parts (American Made Index 2011).

The ranking of the Detroit as a commercial waterway is another area of change for Detroit. In 1945 Detroit had the second largest seaport in the nation. In 2011 its port was ranked, by tonnage, at number 42 (Detroit 2012).

A third visible example of a decline in Detroit's prosperity is its population, which peaked at 1.8 million in the 1950s (Spren and Holloway 2005:35). Its number of residents has declined since then, and the 2000 census tallied its population at below 1 million for the first time since 1930. In addition to numbers, the makeup of Detroit's population has changed radically. From the 1800s through the early 1900s, Detroit's population was made up of people from more than 30 countries from around the world and other parts of the US. Now its population is over 80 percent African American.

"Detroit" is French for "strait," a narrow body of water that links two larger bodies of water. The Detroit River is a strait that links Lake Erie and Lake St. Clair. Because waterways have always been so important for travel and commerce, Detroit was an ideal location for Native Americans prior to the 1600s, for a European frontier fort, and eventually a modern city.

The French bought the land on which Antoine de la Mothe Cadillac built Fort Pontchartrain in 1701. Trading between the French and the Native Americans in the area was considered fair and profitable by both sides, but in 1760 the French lost a war in Europe to the English, and as part of the terms of victory, ceded Detroit to England. Although the Revolutionary War ended in 1783, Detroit remained in the hands of the British until 1796 because England considered Detroit too important to give up (Foster 1972).

The fort's African American presence was first recorded in 1750, when 33 enslaved Africans were in Detroit. By 1782 this number had increased to 179 because, during the Revolutionary war, enslaved people were captured along with "rebel" landowners and brought to the fort (which was in English hands).

A number of factors drew more people to Detroit. The opening of the Erie Canal in 1825 caused its first population boom, from 2,222 in 1830 to 45,000 by 1860. The Erie Canal cut travel time from New York to Detroit from one month to five and a half days (Foster 1972).

Probably few people recognized the radical shift that was beginning for Detroit and the world when Henry Ford built his first car in 1896, and Ransom Olds built the first factory to produce cars in 1899. Dave Buick and the Dodge Brothers followed. By the 1930s the auto industry had drawn more than one million people to Detroit. Henry Ford paid the unusually high wages (Foster 1972) of \$5 per day!

Although the auto and other manufacturing industries were so important to Detroit's development, the dependence on manufacturing caused serious problems when these jobs began to leave. In the 1950s, for instance, the Hudson, Studebaker and Packard Plants closed, causing a loss of 100,000 jobs (Spren and Holloway 2005:56).

Detroit, however had long years of prosperity, and was described as "America's showcase city" in the mid 1920s. It represented the best in urban living and the benefits of industrialization (Gavrilovich and McGraw 2000: 45). Sports, cultural and commercial venues such as Olympia Stadium, the Detroit Institute of Arts, the Detroit Zoo and the Ambassador Bridge all opened during this period.

Unfortunately, the seeds of some of Detroit's later problems were also being sown. Two quotes from 1927 illustrate that Detroit's bounty was not being shared by all of its citizens. From *World's Work Magazine*: "There are no tenements in Detroit. Wages are high, hours of labor are short. The schools are a boast of American

Education” (Gavrilovich and McGraw 2000:45). But this description applied to life for *most* Detroiters. From *The New York Times*, 1927: “The city has its areas of bad housing. It has not provided adequately for its colored population of more than 83,000—almost 90 percent of which have come since World War 1” (Gavrilovich and McGraw 2000:45).

In the early 20th century, due to WWI and other conditions, few immigrants were coming to Detroit. During this same period, the boll weevil decimated crops and agricultural job opportunities in the south, leading to the beginning of the black migration. Many African Americans left the southern farm life and moved north, seeking jobs in the factories and a better life.

Later, when large numbers of southern blacks and whites came to Detroit to fill jobs created by WWII, racial tensions developed, fueled, in part, by southern racial attitudes being transplanted to a northern city. The city wouldn’t permit public housing integration, and in 1943 white workers at the Packard Plant went on a three day strike because three black workers were hired to work beside them (Gavrilovich and McGraw 2000: 47).

Thomas Sugrue (1996) discusses the hiring and promotion discrimination that characterized the practices of too many employers, which was especially evident after WWII. For example, black workers who had become skilled tradesmen (such as welders) during the war (when labor shortages opened up more opportunities for them), were not able to secure positions based on their skills. Black workers were often confined to jobs that were the most poorly paid and offered little chance for advancement.

As Detroit's population boomed, available housing did not keep up. Good affordable housing was especially a problem for African Americans (Sugrue 1996), who were mostly confined to two areas of the city: Black Bottom (named for its rich black soil) and Paradise Valley (Young and Wheeler 1994:16). These were areas of "arrival" for many groups of immigrants, and for a period they had a very diverse population that included blacks. However, unlike other groups, black citizens were not welcomed in "better" neighborhoods, which would have allowed them to move "up" from the poor housing in these locations; they were forced to double up in the housing that was there. By 1930 Black Bottom was almost all black.

There was a very positive side, though, to this segregated community. Since Black Bottom and Paradise Valley were the areas where most African Americans had to live, they started and maintained prosperous businesses there for many years. Paradise Valley in particular had a thriving entertainment venue which drew large mixed crowds and big name black performers like Duke Ellington and Ella Fitzgerald (Metoyer and Watson 1998:vi). By the time Black Bottom was torn down in the 1960s for I-75 and urban renewal, many economic and social issues had caused it to decline significantly.

Although the musical richness of Paradise Valley dissipated, Hitsville, USA and Barry Gordy's recording studio transformed music the way the auto industry transformed locomotion. The "Motown Sound" placed Detroit's creativity on the world stage. Motown was started in 1959 in Detroit, and moved to Los Angeles in 1972 (Motown Historical Museum).

The Great Depression and WWII greatly depressed the construction of new homes, but after the war housing construction flourished in Detroit. Black professional families, or those with higher incomes, were able to move into a few other neighborhoods, which soon became all black. The rate of home ownership in these neighborhoods was actually higher than in the city in general (Sugure 1996). Unfortunately, economic and social challenges kept many black citizens in substandard housing and neighborhoods. In more recent years, financially stable black citizens are also leaving the city for suburban communities, leaving Detroit with a larger and larger percentage of low income population.

When education serves its purpose, it is a great equalizer, giving people the vision and skills they need to overcome the economic disadvantages of the family in which they were born. In Detroit's early days families provided education for their children—tutors or boarding schools for the wealthy, home schooling (or none) for others. In 1804 Father Gabriel Richard started a school in Detroit for white and Indian children (Foster 1972).

Detroit's free public education began in 1842. Black students attended school at a church until schools were integrated in 1869 (Foster 1972). But Earlie M. Poole, born in 1914, noticed that as the integrated high school she attended, Northwestern, got a larger black population, the curriculum changed from college prep to vocational (Moon 1994). She wanted to become a typist, a desirable career for women during that time period, but remembered being asked, "Who would hire *you* as typist?" The public schools were beginning to contribute to limited job opportunities for their black students by limiting their educational options.

By the mid 1960's huge educational disparities existed: Detroit Public Schools spent \$500 less per pupil per year than did school districts in the surrounding suburbs (Young and Wheeler 1994: 181). Detroit's high school drop-out rate was 50 percent. The Kerner Commission Report, commissioned after the many riots of the mid 60's, pointed to the failure of the head of the household to graduate from high school as being, "the most pertinent single factor in the perpetuation of poverty".

However, 50 percent of Detroit high school students *were* graduating at that time, and many attended and graduated from college—especially in the late 1960's and early 1970's when a college education was affordable for working class families, and scholarships were plentiful. Unfortunately for Detroit, large numbers of these graduates—white and black—did not resettle in Detroit. The "Brain Drain" that has been observed in the state of Michigan has long been a characteristic of Detroit (French 2009).

Detroit Public Schools' 2011-2012 Profile Reports show that many Detroit Public High schools have a grade of C or below; some have a grade of D. A comparison on the website www.MI-School.net shows a significant difference between 2010 ACT scores for the top Detroit Public high schools (20.9 at Detroit Renaissance), as compared to the top suburban schools (23.8 at Bloomfield Hills Andover). But more striking than that comparison, is the one between Detroit's best schools, and the scores at some of its "regular" high schools (13.3 at Mumford, 13.4 at Kettering). Detroit Public Schools' failure to prepare all of its young people to function successfully in the world of work has sentenced too many of Detroit's citizens to a life of economic uncertainty.

The quality of health care has a major impact on the quality of one's life. In the early years of the United States, health care was given in the home by family members, possibly with visits by the doctor. However, because early Detroit had men stationed in a fort, sick quarters were established, which were precursors to hospitals. A report dated June 24, 1790 describes the stockade's hospital as "one room entered by 2 doors, equipped with 21 single berths..." (Elderweb 2012).

At the time of Detroit's 1834 Cholera outbreak, most "hospitals" were "poor houses"—designed to care for the poor and the sick. Detroit's first modern hospital was St. Vincent's, which was opened in 1845 by four Catholic nuns (Gavrilovich and McGraw 2000). It was one of several Catholic hospitals providing care in the mid 1800s. Harper Hospital was the first protestant hospital, opening in 1863, and Henry Ford began construction of his hospital facility in 1909. Detroit Receiving Hospital, owned by the city and founded in 1915, was a great improvement on "poor houses" though it served the same purpose: providing care for everyone, regardless of ability to pay (Detroit Receiving Hospital 2012).

"Everyone" though, did not include black citizens. Hospitals were segregated and most did not provide care (or quality care) for black patients. Black doctors were not given hospital privileges as late as the mid-1950s (Gliem 2000). Early in the 20th century, black physicians and community groups began to open their own hospitals. Not only did Detroit have one of the highest numbers of black hospitals, but most of them were owned and operated by African Americans (Gliem 2000).

As integration made it possible for black citizens to receive care at larger hospitals, with state of the art equipment, the black hospitals eventually closed. The

last few shut their doors in 1974 and two merged with non-black hospitals. But African American communities still have fewer health care resources than white communities. Dajun Dai (2010), in his article on health disparities and late stage breast cancer diagnosis in Detroit, discusses the fact that living in neighborhoods with fewer resources and limited opportunities adversely affects health care outcomes.

It is common to point to Detroit's 1967 riots as initiating a permanent downturn for the city, but historian Thomas Sugrue, in a 1998 interview with the Detroit Free Press said, "woes began in the 1950s with deindustrialization, the flight of jobs away from the city, racial discrimination in labor markets and then racial segregation into two metropolitan areas: one black and one white" (Sugrue 1998). The riot had economic anger at its root.

The deaths, arrests and huge destruction of property during the 1967 riot dealt a severe blow to the city of Detroit. Programs designed to assist black youth whose unemployment rate was 25-30 percent at the time of the riots (Sugrue 1996:273), were unable overcome deep seated realities of deindustrialization and the far reaching effects of discrimination, such as inadequate education.

The mid-1970's were also a very challenging time for the city. Housing and Urban Development (HUD) brokers approved loans for people who didn't have the income to make payments (Gavrilovich and McGraw 2000:51) which contributed to an increase in thousands of vacant homes. The auto industry was not competing well with fuel efficient cars from Japan and Europe, and automobile manufacturing jobs were being transferred to other parts of the country. Drug use was causing devastation in

families and communities, especially due to the related increase in crime and the negative example of material wealth flaunted by drug dealers.

The recent economic woes of the country and world have had the effect of kicking the city while it's down. Many years of challenges in areas of housing, employment, education and health care are factors contributing to the percentage of Detroit's population who don't have the skills, support, opportunities or vision to make their lives productive and comfortable. There are always citizens who strive diligently against odds that are not in their favor, and who succeed, but those who just put forth "ordinary" effort, are often unable to overcome the obstacles (external and internal) that keep them in less than ideal circumstances.

Health of Women and Children in Detroit

Although the tables and statistics provided in this section provide a brief view of data on the status of women in children in Detroit, they are not designed to capture or express the diversity of the health experiences of Detroit area families. Instead they offer an overview of the challenges faced, and highlight the rationale for selecting families from this region to provide explanatory models of risk.

In 2009 Michigan was ranked 27th in the nation by the *Kids Count* overall ranking, that included the sum of the scores for the ten key indicators of child health, including low birth weight babies, infant mortality rate, child death rate, teen death rate and teen birth rate. The other five are teen drop-out rate, teens not attending school and not working, children in families where no parent has year-round full-time employment, children in poverty, and children in single parent families. Overall, Wayne County residents have a higher percentage of new mothers under 20 years of age, unwed

mothers, mothers with less than 12 years of education, teens 15-19 years old with repeat births, women with late or no prenatal care, and infants born prematurely or with low birth weights.

Mothers in Wayne County have consistently lower levels of high school completion than the state average. In 2009, 34.9 percent of mothers did not have a high school degree compared to 16.9 percent statewide (Table 1).

Table 1.
Profile of Mothers and Children in Wayne County and Detroit 2009

	Wayne County (number)	Wayne County (percent)	Detroit (number)	Detroit (percent)
No Diploma or GED	5,992	23.8	4014	34.9
Teens	3,495	13.6	2440	20.8
Unwed	13,780	53.8	9119	77.8
Unemployment	140424	16.2	94,290	25.0
Child insured by Medicaid	253,431	47.0	154,057	61.8
Child receiving FAP	207,537	38.5	128,311	51.5
Preterm Births	3028	11.8	1708	14.6
Low Birth Weight	2671	10.4	1526	13.0

Kids Count Data center 2009

Population growth in Wayne County came to a halt in 2002, when there were 2,052,396 residents. As of 2009 that number had diminished to 1,925,848. This loss of population, primarily from out-migration, has seriously impacted the number of births in the county. In fact, there has been a steady decrease in births since 1990, when there were 40,680. In 2009 the number was 24,646. However, the drop in births has not been the same throughout the county. While there was a drop of 14 percent in Out-Wayne County, births decreased by 49.5 percent in Detroit (US Census Bureau).

In Tables 2 and 3, the numbers of live births by level of prenatal care, by race, are described in Wayne County and Detroit. Of the 26,646 live births in Wayne County in 2009, there were 11,320 whites, 11,492 blacks, 2,000 Arabs and 1,884 Hispanics.

Table 2.
Births by Prenatal Care by Race and Ancestry of Mother
Wayne County Michigan Residents, 2009

Kessner Index

Race or Ancestry	Total			Adequate			Intermediate			Inadequate		
	Live Births	Low Birth Weight	%	Live Births	Low Birth Weight	%	Live Births	Low Birth Weight	%	Live Births	Low Birth Weight	%
All Races	24,646	2,623	10.6	14,603	1,352	9.3	5,230	609	11.6	2,980	426	14.3
White	11,320	828	7.3	7,889	540	6.8	1,990	148	7.4	978	102	10.4
Black	11,492	1,622	14.1	5,534	714	12.9	2,899	424	14.6	1,836	304	16.6
Ancestry												
Arab	2,000	135	6.8	1,155	75	6.5	436	30	6.9	312	22	7.1
Hispanic	1,884	141	7.5	1,117	77	6.9	482	36	7.5	168	13	7.7

2009 Michigan Resident Birth File, Division for Vital Records & Health Statistics, Michigan Department of Community Health

Table 3.
Births by Prenatal Care by Race and Ancestry of Mother
Detroit, Michigan Residents, 2009

Kessner Index

Race or Ancestry	Total			Adequate			Intermediate			Inadequate		
	Live Births	Low Birth Weight	%	Live Births	Low Birth Weight	%	Live Births	Low Birth Weight	%	Live Births	Low Birth Weight	%
All Races	11,199	1,491	13.3	5,208	629	12.1	2,921	376	12.9	1,831	298	16.3
White	1,404	92	6.6	676	42	6.2	430	24	5.6	238	20	8.4
Black	9,076	1,328	14.6	4,139	552	13.3	2,340	339	14.5	1,529	270	17.7
Ancestry												
Arab	303	19	6.3	140	9	6.4	73	4	*	64	3	*
Hispanic	1,181	95	8.0	615	49	8.0	353	23	6.5	121	10	8.3

2009 Michigan Resident Birth File, Division for Vital Records & Health Statistics, Michigan Department of Community Health

Black women accounted for the highest number of cases of inadequate prenatal care, 1,836, based on the Kessner Index (see Appendix F for definition), and 16.6 percent of these deliveries were preterm (Table 2). For the City of Detroit, 17.7 percent of women with inadequate prenatal care delivered preterm (Table 3).

While prenatal care, income, education and other factors are all associated with birth outcomes, the disparities in preterm and low birth weight for African American infants are not explained by these statistics.

Summary

Detroit was a city that once offered African Americans a secure, middle class life style. Although discrimination certainly existed, families for many years, regardless of ethnicity, could enjoy going to the Detroit Zoo, Bob-Lo Island, Belle Isle, the Detroit Historical Museum, the Detroit Institute of Arts, sporting events, and the many other recreational, artistic and cultural outlets that characterized “Motown.” There were good homes, good schools, good jobs and families could live in dignity and look forward to a multitude of opportunities for growth and advancement. Much has changed. The housing crisis, disintegration of neighborhoods, high unemployment, the flight of industries and businesses, the loss of major retail chains and high crime have all had a major impact on the health and well being of the citizens of a city that is over 80 percent African American.

Detroit’s seal has two women on it, with a burning fort in the background, commemorating Detroit burning to the ground in 1805. Its motto is “We hope for better things; it will arise from the ashes” (Foster 1972). But, until it does, too many residents of Detroit live daily with insecurity about most facets of their lives. Talking to the

residents in this setting, who must daily confront, and reflect on the multitude of exposures that have impacted their lives, provides an opportunity to understand how risk is perceived and explained by those most deeply affected.

CHAPTER 7

CASE STUDY 1- RISK IS EXPLAINED BY MATERNAL BEHAVIORS

“It ain’t about you anymore, it’s about the baby”

When Stephanie Walker shared this advice, she was an inpatient on the Antepartum High Risk unit. Stephanie was widowed, with three daughters and was a Certified Nursing Assistant (CNA). At 31 years of age, this was her seventh pregnancy and her third time experiencing preterm labor symptoms.

Illness Experience

With her first pregnancy, her daughter was born full term, and there were no complications. However, when this daughter was nine months old, Stephanie learned that she was four months pregnant, and was carrying twins. They were born by cesarean section at 24 weeks gestation, and did not survive. She explained what occurred.

The day I went into labor one of the twins, one was coming out breech. And with that pregnancy I was doing so much I was working, catching the bus, and taking care of my daughter, you know, I was going through a lot right then and there too. So I think a lot of that had to do with me having them early, them coming early. I was 24 weeks and after I had them in March, then in July then I got pregnant again.

In this short statement, Stephanie alludes to two possible explanations for the preterm labor. The first, “doing too much” was a theme repeated with many of the women in the study. The second, though not as clearly stated, was that she was “going through a lot.” This was not in reference to her numerous responsibilities or multiple activities, but to stressful events of a psychosocial nature. Shortly after the loss of her twins, she conceives again, unintentionally.

Stephanie terminated this subsequent pregnancy because she said she was afraid of what might happen to her body so soon after having a C-Section. She did not believe her body had been given adequate time to heal properly. The following January, six months after the termination, Stephanie once again found herself pregnant. She explains,

. . . so here come January and I'm pregnant again with my 8 year old and I was fine with her, I went as far as 31 weeks when I had her though, cause my water bag had ruptured . . . she was fine, she stayed in the hospital like for 3 days and then she only needed to nipple, she didn't have no jaundice no complication or none of that, she was four pounds and three ounces so she was fine. And then, when I came home with her, six weeks later I get pregnant again with my 7 year old, and she was fine, I had her full term.

For her fourth and fifth pregnancies, just described above, Stephanie said everything was fine. Although infants born at 31 weeks do often survive intact, they face challenges later in life that are not immediately apparent at birth. Stephanie indicated, though, that since this daughter did not have to stay in the hospital for an extended period, or have any of the common complications seen with infants born prematurely, that this was a good outcome. After having had five pregnancies in three years, all with the same father, Stephanie did not become pregnant again for seven years. She spoke of how she was able to spend time with her three daughters and be a good mother to them. She continued the chronology of her pregnancies, referring back to the fifth pregnancy that resulted in a full term birth.

And I hadn't been pregnant in seven years after that happened [referring to her fifth pregnancy, which resulted in a full term birth]. They dad passed away, so, um I'm with someone new. We just got pregnant last year with twins...a boy and a girl and she, my twin A, ruptured her water bag, and her water bag broke, and I wasn't here at Women and Infants Hospital, I was at St. Christopher's Hospital and I felt like they could have prevented a lot of stuff from happening but they be so tied up on how many weeks pregnant you are and whatever, they just didn't want to do stuff if I wasn't 24 weeks yet. She ended up dying, and I had to push

her out . . . and then 13 hours later, my son came out and he was doing fine. The first three days he had a problem with his sugar, but they stabilized it, next thing I know they said they gave him morphine so he could calm down because they said he was moving, active, and they said that wasn't good for him, and next day his heart stopped. So that was another thing I was going through, and that is why I'm never going to that hospital, ever again.

Stephanie was particularly saddened by the death of the male twin because this was her first boy. She believed that the hospital staff did not take saving the twins seriously, because they did nothing to stop her labor. She complained that they were not concerned because she was not quite 24 weeks gestation. In general, 24 weeks gestation is considered the age of viability, and heroic efforts are often not expended at less than 24 weeks. This troubled Stephanie greatly, because she thought that her care providers should have intervened to stop her from delivering before 24 weeks, to give her tiny infants at least a small chance to survive. She also believed that the administration of the morphine hastened the demise of Micah. Because Michaela was stillborn, she accepted that there nothing that could have been done to save her, but she had great difficulty accepting the loss of Micah.

And then after that, 6 weeks later, as soon as I stop bleeding I'm back pregnant again. I think it seems me getting pregnant so quick and not like letting my body rest, kinda got a lot to do with the premature labor and stuff, and like before I got pregnant with the twins I just lost. Last year, well I'm a CNA and I do a lot of pulling and tugging and my body been tired for a long time, like cause I don't never take no vacations or stuff like that, you know I wasn't prepared to be pregnant you know, and I think a lot of that took a toll on my body.

Explanation of Causality

Stephanie is trying to make sense of the loss, but she places the responsibility squarely on her own shoulders. She gives two explanations. Her model revolves around the stress she placed on her body. She was a CNA, doing heavy lifting and moving of patients in a nursing home. The strain on her body was what she felt led to

her early labor with the second set of twins. Next, she explained that she did not let her body properly recuperate after the twins were born. Her lament that she never takes vacations and that she was not prepared to be pregnant can be interpreted as not only referring to her physical being, but her emotional state as well. She does not get a break. Now she is once again experiencing preterm labor symptoms, despite her efforts to control outside responsibilities and stress.

And like now this done happened, like I done dilated, and I'm not doing nothing, I'm not stressed out , I took off work earlier, I did the stuff I was supposed to did . . . like the last pregnancy with the twins I just lost, I didn't take off work I was still working and all that stuff, but this time I try to be careful, I took off work and I was doing all that, I stayed off my feet at home, I not stressed out and then this happened. I think my body just needed rest.

By listing the lifestyle changes she made for this pregnancy, she implies that she does not understand her current predicament, yet she ends the statement concluding that there was something she could have done. Her body needed rest, and she did not give her body that rest. So, I asked her if she believed there was something could have done differently. She did.

Like, I feel any pregnant woman should know when enough is enough. You got those voices in your head that tell you to sit down but like when you so used to doing it by yourself, everybody don't have the proper support system behind them, and me and my three girls, they all I got, and Deon just walked into our lives, so he eased a lot of that up, but my girls still depend on me, you know what I'm saying? And I feel like if I don't do it, who else is going to do it? You know, I think about just chilling out, not doing nothing, just letting the house be dirty, I couldn't do it! So you know it's like either, or, but not doing nothing, letting the house be dirty, I can't deal with that. So you know so it's either, or. But so far, so good. I haven't been stressed out, and I have been having people come and help me clean up, Deon is more better, and supportive, and he's so sad because he feels like it's his fault 'cause I gotta stay here.

As Stephanie continued to try to explain her current experience with preterm labor, she suggested that she believed her sexual activity was impacting her preterm labor symptoms. When I asked her to confirm this, she said,

Yes, I think that's why I done dilated. We don't be having rough sex like that, you know, cause my stomach big and stuff, so we don't be doing all that but it still happen. That's the only thing I can think of, because I don't be walking, you know I don't be doing nothing. That's why I dilated early, but just I need to take a break. Sew it up and throw away the key for a while. The baby factory needs to be shut down! And I got so much I need to do. I need to go back to school. And, I gotta make sure these girls is straight. I can't have no house full of kids like that. I'm not doing it by myself, but you know you never know what's going to happen, life is crazy.

Personal Responsibility

Stephanie continually returns to her discussion of what she could have or should have done differently and she locates the risk within her own behavior. Her explanations cover a variety factors that she views as contributing to poor pregnancy outcomes, including the pregnancy interval, worry and stress, and a lack of adequate rest.

I shouldn'da got pregnant so quick again and stuff, you know. I lost two sets of twins, that just hurt me. Then I had my first son, and I couldn't have him. But everything happens for reason you know, I don't let it drive me crazy but I know that they with God, so, they good, you know. . . But I feel like I coulda did different things like not all that stressing and working and stuff like that but my body is tired and I feel like, after this, I'm not getting pregnant quick no more, I really do, I'm really going to do birth control and all of that stuff but I didn't really think I could have no more kids after my last daughter that's seven because I haven't been pregnant in that long, it's almost seven years.

Spirituality

In this passage Stephanie makes the first suggestion that maybe some of what occurred with her pregnancies was beyond her control. She begins by noting that her pregnancies were too closely spaced, something over which she did have control.

However, in recounting the loss of her twins she says that she cannot let it “drive her crazy,” and that they are with God. While she is saying she cannot be overly worried about this, she is still communicating a serious and abiding concern. “Everything happens for reason” is often a spiritually motivated statement invoking the presence of a higher power, but it does not dismiss her concerns. The concept is intended to allow her a means to find peace with the losses, framing the events as being divinely ordered. Yet, she still goes on to question why her outcomes are poorer than those around her.

I know some women that can't never carry their babies full term. But they come out 6 months, 26 weeks, 27 weeks, and their babies live and their babies be fine and don't nothing be wrong with them. It was like when I have them, all my babies die, and I be like what, what is this? But I guess it's different strokes for different folks.

Stephanie had a strong emotional investment in the second twin pregnancy, and, as will be discussed later, research in perinatal loss has shown how this impacts her attitude toward her current and any future pregnancies. She believed the twins were a special gift.

And I feel like one of them special people, because it takes special people to have twins. And I had a chance to be pregnant with them twice. And probably down the road, I'll probably have another set. . . I'm not mad about it. I am upset about it, but I don't hold no grudges, but the last twins I just lost. . . I have a lot of concerns about them, and what they could've done differently because they was just so, just so unprofessional. Like, how you come through emergency and you in labor . . . they didn't even try to stop my labor, I wasn't even in labor, my water bag just ruptured. But they didn't try to give me nothing to prevent anything from happening. They just let me ride [did not intervene] Then I just sat there and bled for two days, nobody wouldn't check my cervix. It was a bunch of stuff that was going on. That you wouldn't even think that a hospital with that type of [reputation]. . . they so professional, that something like that would happen.

While Stephanie was most unhappy with the care she received at St. Christopher's, her complaint about medical care was specific to that institution. She said she was happy

with the care she received at Women and Infants Hospital, and she spoke with great affection, pride and respect about her obstetrician, Dr. Eaton.

Man, I love Dr. Eaton. Dr. Eaton been my doctor since I had the baby that came at 31 weeks. Even if I missed an appointment she was at my house (imitates by knocking on her bedside table). Yes, I trust her completely. . . . Yeah first thing in the morning, before she do anything . . . but she comes to see about me. And she's always been like that. And everything she says goes. She tell me I got to stay here, I'm not like, 'I'm not going to stay here.' Yeah right, I'm going to stay here before anything happens.

I asked Stephanie what Dr. Eaton had told her regarding this pregnancy. Ideally, when the doctor-patient relationship is viewed by the patient as very good, the communication between the two should also be very good. I wanted to hear what Stephanie understood about her doctor's explanatory model in comparison of her own.

Like, Dr. Eaton is real concerned, she want me not to do nothing and bust my water bag and make my water break. She told me this the best place for me to be right now, and I'm gonna listen to my doctor. It's just right now I'm like, I really haven't did much shopping for the baby and I know all that'll come. I did some stuff, but I'll get it together. But I'm just like forget it, if I have to lay here all day, I'll just lay here all day. That's about it.

Perceptions of Risk

One question I asked all of the participants was whether they felt safer in the hospital than at home. It was my intention to elicit notions regarding agency (things they could do for themselves), responsibility (whose job it was to keep her safe), and attitudes regarding the biomedical model of care.

I don't know, sometimes. 'Cause I'm not supposed to be up walking around, and I know if I was at home I would be up doing something. As far as going in the bathtub by myself, I been stopped that. Deon, when I take my bath, he be in the bathroom with me, he help me out. A lot of things I don't do, I don't let happen, he be with me all the time, he my support person, but shoot, if they going give me injections everyday then they may as well let me go home. I'm not going to go in labor.

The idea of being at home is often extremely appealing to women hospitalized on bedrest, even when they strongly believe that remaining hospitalized is critically important. For Stephanie, she admitted that she would have more difficulty maintaining bedrest at home, but then explained that her partner would help make sure she expended as little effort as possible. She also rationalized that if her doctor decided to give her injections then she could just go home, because the medication would prevent her from going into labor. Much of her desire to be at home, though, related to her desire to be a good mother and home maker. She criticized women who continued to have children, but could not properly take care of them.

I live up to my responsibility, yeah I had kids back to back, yeah I been pregnant and I probably shouldn't be, but whenever it happen and I have these kids, then I know I can take care of them, you know what I'm saying, but you don't need no bunch of kids at one time like that, it's not healthy for the kids, or you, because every child, individually is going to need their attention. And you can't say, well I'll get back to you and go to that other one, you know what I'm saying, it's not fair for the kids. Truth is it's not fair on me because that's stressful. But I love my kids, I don't regret nothing that happened cause everything happens for a reason.

Again Stephanie returns to the phrase, “everything happens for a reason.” As we continued to talk, Stephanie told me that did take some risks and confided that she engaged in an activity that she was not comfortable admitting.

Well, I started smoking when I was fifteen. Why? I couldn't tell you. But I have been smoking since I was fifteen years old. I don't like it half the time, sometimes I'll chill out [stop], then I'll go back. But it's a habit now, so it's like, it be hard to break, but I know it's kids I got, so I can't do it. I don't know why I smoke (very animated) I couldn't even tell you. I mean it feel good if you smoke a cigarette after you eat or something, but just sitting there I'll need a cigarette. I just do it, right? (laughs) You know, like I know it ain't funny so I just need to leave it alone.

I followed with this question, “Is that what you meant when you said you do take risks? Is that something you consider a risk?” And she responded,

Yeah, you might as well say. It makes no sense. Just smoking, so what is the reason? Just go light a cigarette? What are you smoking it for? There's a risk. That puff might make a hole in your throat or something. You never know.

Living Environment

As we continued to explore the ways in which Stephanie discussed risk, I inquired about her neighborhood and living environment. Numerous studies have shown a relationship between neighborhoods and the rate of preterm birth, so it was important to understand how she viewed her living situation.

It's just livable. It ain't the best, and it ain't the worst. But it's livable, but I could see what it's coming to. And then like they closing all these schools, and all these kids from different areas just, they tearing up everything. These kids cuss, they come out school you hear them cussing better than grown folks. They worse! At the school my kids go to, it's an academy, that school was really nice and stuff. Now, it's just whatever. I know I don't want to live over there no more. Violence and shooting, I probably try to go to [the suburbs] but I know I can't afford that. But I'd do anything for my kids, I'll tell you that. Somewhere where there's a better school district and stuff, Detroit is just so messed up right now."

In the concluding portion of this interview, Stephanie discusses how she will plan for the next time around, and gives her own "prescription" for healthy pregnancy.

Well if I was actually going to be pregnant again, it's going to be planned. I'm not just going to get pregnant, being naive. I'm going to plan it. I won't have to do nothing. I'm going to chill out, take care of myself, properly. I'm not just going to have no baby, just cause I got lost, caught in the moment, that night (laughs). No more, that's not going to happen. Make sure that my body be right, and I'm ready, you know?

Throughout this interview, Stephanie portrayed herself as the one primarily to blame for her pregnancy complications. Her explanations included doing too much work, doing work that was too strenuous, not getting enough rest, not allowing adequate spacing between her pregnancies, and, in general, not taking care of herself as best she could. She also talked about her diet and nutrition, and how she knew she was not eating properly. However, in this discussion she also revealed a moral framework that

informed her actions. She was a mother, a breadwinner, a homemaker, and a wife. There was evidence of a hierarchy of responsibility for those roles. So while taking care of her fetus, through taking care of herself, was important, it had not superseded her desire to provide for her family in the all the manners that she believed were necessary. In the next section the perceptions and explanations of her family are explored.

Stephanie's Home

I returned to Stephanie's hospital room one week after the initial interview. I had spoken with her the evening before, and she told me her husband would be coming around noon, and I could interview him also at that time. However, when I entered her room she told me she just had been discharged a little earlier that morning, and that she and her husband were ready to leave. I asked if I could come to her home to complete the interviews and she agreed. She provided me with the address and directions and I drove there the next day.

The homes in this once attractive east side neighborhood were now in various states of disrepair. The architecture of the homes, typical in many neighborhoods in Detroit, was a mix of moderate sized versions of English Tudor, Colonial Revised and brick bungalows. Some of the concrete steps and brick supports for the porches were crumbling. The windows in many homes on the block were boarded. The overall appearance of the area was not complete desolation, because many homes on the blocks were well maintained, with fresh paint, neatly manicured lawns, and tasteful flower gardens in full bloom.

When I parked my van in front of the home, there were two men on the sidewalk standing astraddle bicycles, who appeared a bit out of place by age and attire. I

assumed one was the participant's husband when he asked if I was going to visit Stephanie. I told him I was, and proceeded up the stairs. I knocked on the door, and a young man answered the door. I introduced myself and he invited me in. I came inside and stepped from the foyer directly into the living room. Stephanie was sitting on a black futon that had been laid flat for sleeping, with multiple pillows stacked at one end. The futon was by the large bay window in the front of the house. Directly in the opposite corner of the living room was a large screen television that was turned off upon my arrival. The only other piece of furniture in the living room was one chair. Stephanie, wearing a stylish black and white print pajama set, greeted me warmly, with a big smile. The walls in the living were painted a deep purple and the wood trim was painted in lavender. The room seemed dark, despite the sunshine outside. There was a wide open archway between the living room and dining room. In the dining room there was one table, and one chair.

Stephanie introduced me to her husband, Deon, the young man who answered the door. He escorted me to the dining room and invited me to sit in the one chair. He then brought the other chair from the living room and sat down. I introduced the study, and read over the informed consent with him. He signed it quickly, and looked towards the front door several times while we were recording the interview. After I paid him the \$25.00 for completing the interview, he got up to leave. Stephanie asked him to buy her some juice when he went to the store. He said he would. She smiled again and winked at me. One of the young men who had been on the bicycle when I arrived was now at the door waiting for Deon. They left together. I then sat next to Stephanie and proceeded to conduct the next interview. After completing all of the forms, I gave

Stephanie her \$25.00 for the second interview. She said she was surprised that she was receiving another \$25.00 and asked me not to tell Deon that she had it. She said that if he knew, then he would want her to pay for her food and snacks out of her own money, rather than using his. Several actions and comments by Stephanie indicated a tentativeness and slight lack of ease in her relationship with Deon. I later learned that although she referred to him as her husband, and as I will continue do, he actually was not. The content of the interview with Deon is detailed below.

Deon

Stephanie's husband, Deon, spoke very lovingly of his wife, but explained her condition somewhat differently. Even though he used some of what I suspected were her words in terms of what could be done to prevent a preterm birth, he expressed a sense that the prematurity may be inevitable.

I mean, you can't never do nothing to prevent nature. Nature is going to take its course naturally, but I mean you do things to try to prevent it, you know, stay home, not stressed, eat the right foods, take your vitamins, you know, you can do all the things you can do, and anything after that, it just naturally, everything is going to take its course.

He said he saw that his wife, "got a higher risk than the average woman being pregnant" of having a premature baby, or one with complications. He told me that they discussed this when they first met and talked about having children. I asked why he thought this was a problem for her.

It ain't necessarily anything particular with her, it's just women in general your body go through things, you know they shut down they don't react . . . the way you eat, you don't exercise, you might smoke, you might do drugs, it's a reaction to your body and some people's body are just genetically made up like that and they can't hold that pressure.

In probing with Deon the idea that genetics were involved, he said that it would have to be something like that because he could not see another reason. He was, however, encouraged by what was going on with the current pregnancy. He said that he believed that, “too much stress, yelling, staying on her feet, and work” were contributing to her problems in the past, so he was now making sure Stephanie stays off her feet, takes her vitamins and medication, and adheres to complete bedrest.

Well actually this pregnancy is a lot more better than the other pregnancy because my daughter is lot more happier (referring to the unborn baby) and at this stage last time her water had broke previously which led to the other complication of me losing my twins. I felt like she's doing excellent now. . . , I mean she don't work no more, I just take good care of her I want my baby and her to be right. . . I help out with everything. That's my baby!

However, he expressed the same type of ambivalence Stephanie did about her being at home.

Me, personally, I think she's safer being in the hospital. There's no home safer than the hospital where there are physicians, doctors, things of that nature, but I feel like, you know what I'm saying, she's safe enough to be at home, cause she needed to be at home. That's part of her being stressed out at the doctor [he uses this term to refer to her being hospitalized] worried about what the kids are doing, what about this, you know what I'm saying, she need to be at home, but if she need to be at the doctor, trust me, she'll be there.

While emphasizing that they will make sure Stephanie receives the medical attention she needs, he again alludes to perhaps a predestination, divine order or fate to the timing of the birth.

I think if she do come early, she going to come when it's time for her to come, like I said her water hadn't broke or none of that stuff so I feel like she only seven months but it's these last two months that really. At eight months she good, and my baby healthy, she bigger than the twins was, so you know . . . I don't think the baby gonna have no complications. I know my baby is gonna be active, and okay.

Deon expressed a high level of optimism regarding the outcome of the current pregnancy, but was not convinced that women, in general, could do much to prevent a preterm delivery. His mother-in-law, however, saw Stephanie as having more accountability for her condition.

Sherry Carter, Stephanie's Mother

Stephanie's mother, Sherry Carter, worked in a social service office that was less than a ten minute drive from Stephanie's home. Following completion of the interview with Deon, Stephanie called her mother to make arrangements for me to go to her mother's place of work for the interview. Stephanie explained that Sherry Carter was not actually her biological mother, but was her aunt (Stephanie's mother's sister). Stephanie's biological mother was unable to raise her, or her sister, so her aunt took both of them as babies, and raised them as her own children. When I arrived at the office, there were no clients in the waiting room. She explained that she had no appointments for the rest of the afternoon because she had a lot of paper work to complete, and that we could complete the interview in the lunch room during her break. There were no other staff members using the lunch room. To begin the interview, I asked Sherry what high risk meant to her.

To me high risk means that she would need to take it easy, not do much strenuous work, her system can't bear it. I don't know what causes it but it's more of a hard time for her to carry a baby, especially the twins. Okay now with the other babies, I don't recall her having such a hard time as she is now, so I don't know if it's part of the system, I'm not sure what it is. I don't know if it's about how she cares for herself, what type of work, I don't know, I don't know if it's stress. I don't know if stressed, depressed, all that fall in, under one another. I'm not quite sure, the only thing I can probably do is guess, not knowing exactly what it is.

Because stress is so frequently linked with preterm labor, I asked Mrs. Carter to me tell me more about how she saw stress as a factor.

It's a possibility, cause I'm not sure. And I can't really hardly speak on it because I didn't have those problems. I had all healthy babies, healthy pregnancies and so forth, no type of complication. So I'm just not sure what it is. I don't know. I don't know if it comes from smoking, drinking, I have no idea. I have no idea what exactly it is. But once you are diagnosed as being high risk I would think you need to go on bedrest, you know kind of like take it easy. The doctor mentioned for her to watch what she's doing, you know, no heavy lifting, more bedrest, just being calm and not doing anything strenuously.

In this explanation Sherry explained stress as overdoing it, or perhaps doing things that were too strenuous. I asked Sherry to share with me her thoughts about why Stephanie was having these problems. She said, "Sometimes I thought, especially with the twins, cause it was two babies, sometimes our system is not quite set up for it, I'm not sure." Sherry continued to express hesitancy or difficulty in suggesting an idea as to why Stephanie was having problems with preterm labor so I next asked if she thought there was anything Stephanie could do to affect the outcome of this current pregnancy.

Probably not, I can't think of anything you could do different, besides preventing getting pregnant. I mean I couldn't think of any other thing that you would do different. She stopped working and that would take off some of that lifting and pulling, all the bending and stooping probably.

Not becoming pregnant may seem a very reasonable and obvious solution to avoiding the repeated complications of preterm labor and birth, yet there are many reasons why women do not make that choice. Stephanie's mother rated the risk very high for this pregnancy and explained why.

Because I spoke to her about that, you had two pregnancies in a row, both of them are twins and to me she's risking herself. Well, with the babies not making it, so ...I told her, what kind of toll do you think that takes on your body? I know my child is grown and I can't tell 'em what to do. So I said after this baby and

everything go fine, then you need to think about it for your health as well as the baby's health. 'Cause when she's stressed, the baby's stressed. I spoke to her, for her to think about it, on not getting pregnant again and taking your body through that. You already have three, you done lost two sets of twins . . . and I know she wants that boy, but sometimes you have to quit, for your own good, for your own safety. So that you'll be able to take care of the children you have, as well as yourself. You know, it's okay, you don't have to have a boy. Yeah, so, it's just worrisome to me, just worrisome to me, (begins tearing up) but I don't need to go there.

This discussion stirred strong emotions for Stephanie's mom. She was worried about her daughter being able to survive all the complications she was encountering. She said she did not understand what kept happening with her daughter, and this lack of insight made her fearful. Sherry's belief was that Stephanie needed to stop trying so hard to have a boy, and to take care of the children she already had. Sherry further explained the reason for her worry.

She's not due [for another 3 months] and we was talking up to two weeks ago that she had dilated to 4 so, I don't know, I just hope she do what she supposed to do, eat right, don't do the things she not supposed to do, as far as putting that strenuous on your body, or be putting that stress on you or the baby, let's see can we make it through this pregnancy, just take it easy. Do the rest that they, I think they call it bedrest, do your bedrest until this time is over. 'Cause she's like my other daughter, they love to work, they are workaholics, they just love to work.

Sherry wanted her daughter to comply with the medical advice, and avoid putting any additional stress on her body. A key point in this statement is that she wants this baby to make it, and does not want Stephanie to go through another devastating loss. She expressed the sadness and disappointment the family experienced.

We were so positive with the last babies. After the girl passed, and she always wanted this boy, we just knew! He just looked so FINE, like if he could just give us a few more weeks or just a day, well I just knew he was going to make it...and he didn't. And that just broke everybody's heart. It just crushed hers, and the daddy's. It was a shock. I don't know what they did [referring to the hospital] but she's where she want to be now with this baby. She do not want to go to St. Christopher's anymore because that where she lost the last twins.

When I asked if Mrs. Carter thought Stephanie was better off in the hospital now than she was at home, Mrs. Carter was not convinced. The opinion she expressed was similar to Stephanie's, that being home was okay so long she adhered to maintaining rest.

No, not unless it's a constant, ongoing thing like if she's got to run to the hospital three times a week or every week or every other week, then maybe she needs to be in the hospital. So this just happened this one time that I know of, so I think she can take it easy at home."

When a mother is hospitalized, this can place additional pressure on other family members to care for the home and other children. Family relationships can become severely strained with repeated pregnancy complications, and Mrs. Carter addressed the impact of Stephanie's ongoing medical problems. She said it was causing a strain in the family and related the response of some family members when they learned that Stephanie was pregnant.

What is she having another baby for now?!" She just lost [a pregnancy] and they go on and on, and yeah, I think so. They think she needs to take better care of herself. I'm not sure if everything is for a reason but folks say there's a reason for this and a reason for that, but you done lost four babies in a row, and they want her to take better care of herself and her body. And just accept what she already have, and be thankful and just raise her girls.

Discussion

The explanatory model constructed by Stephanie implicated her personal behaviors as the cause of the preterm labor that happened so often in her pregnancies. It was a theme that was often voiced by other pregnant women interviewed in this study. While Stephanie's mother shared this opinion, her husband did not attribute Stephanie's behavior to being the main cause of the preterm labor that led to the death of his twins. Her husband explained the risk more as fate, an inevitable consequence for some

women, *“I mean, you can’t never do nothing to prevent nature. Nature is going to take its course, naturally.”*

In listening to and reviewing the discussions with Stephanie and her family, it seemed that having one pregnancy after another, despite serious complications, was an attempt “to get it right.” Stephanie stated that God had blessed her with twins twice, and that made her feel special. She believed that God would bless her again, and that the next time she would be prepared. The pregnancy would be planned, she would not be stressed and everything would work out well. In this discussion she expressed a belief that she could control the outcome of a subsequent pregnancy, despite the fact that she had not been able to do so thus far.

Not only does this family’s story evince an explanatory model that places responsibility for preterm birth on the behaviors of the mother, but it also shows differing locations of risk. As referenced earlier, Kleinman explained that since explanatory models involve tacit knowledge, they frequently are not “coherent or unambiguous” (Kleinman1980:109). While each of the speakers offered a primary theme, they each also moved between several alternate explanations. Stephanie primarily believed her job, which required strenuous work, and her demanding duties as a wife and mother, played a significant role in her preterm labor symptoms. She questioned whether stress, or her smoking, could additionally contribute to untoward outcomes. She also suggested that perhaps there was a divine reason for the loss of her four children.

Her husband mentioned stress and smoking, but leaned heavily toward the belief that control was not in her hands. He raised the question of genetics, but this was because he said he could not see another explanation.

Stephanie's mom, as with other mothers interviewed, was worried about the health of her daughter. She too was upset because Stephanie kept putting herself in this predicament. Mrs. Carter spoke of how family members were upset that Stephanie was once again pregnant. Stephanie had lost two sets of twins, and was now putting her emotional and physical health at risk by getting pregnant again. When Stephanie was hospitalized it meant other family members would need to help with child care and household responsibilities, even though Stephanie did not want to be confined to bed. The current pregnancy had not only taken a toll on Stephanie's body, but on her family relationships was well.

While stress was mentioned in this case study by all three family members as a possible factor in preterm labor, in the next case study, it takes a central role.

CHAPTER 8**CASE STUDY 2: RISK IS EXPLAINED BY STRESS*****“My Plate is Full”***

Precious Perry, at the age of 26, was pregnant for the sixth time. Only one of the five children she delivered was born full term, and she was currently hospitalized for preterm labor at 28 weeks gestation. She had a high school education and had been married for seven years. She had a severe seizure disorder, and asthma. One of the nurses on the high risk unit obtained permission from Precious to speak with me on the morning I arrived, but I had to wait until the doctors, who were in process of making rounds, had finished seeing her. As the last of the group of doctors emerged from her room, I asked one if it was okay for me to go in. He told me she was extremely upset at the time, so I asked him if it would be better for me to wait until later. He said, “Oh no, not at all. Please go in and talk with her, I think you will be good for her.”

When I entered her room, Precious was sitting upright in her bed, with one leg crossed under her, and looking at the cell phone in her right hand. She looked up at me and said, “Come on in,” but she was crying. I introduced myself and asked if I should come back at a different time, but she said, “No, no I need to talk to you.” I asked her if there was something I could do for her, and she said, “I am so upset, let me tell you what just happened! Somebody stole my money!”

At that point I thought that maybe I should contact her nurse, and ask to have security paged, but Precious proceeded to tell me what occurred. She had recently “come into” a sum of money, and a good friend of hers asked to borrow \$1,400, promising to pay it back in matter of days. Precious said she had been really reluctant

to loan the money, but trusted her friend, and believed she helping her out of a desperate situation. Now the friend was saying that she had no means to pay back the money. Precious believed her friend had lied to her in the first place about the urgent need, and in the second place about how it would only be a few days before she could pay it back.

Precious was both hurt and angry, and said, “I am under so much stress, no wonder I am always in the hospital!” Precious spoke for another 10 minutes or so about the circumstances of this “theft” and how angry and hurt she was but then she gradually calmed down. I proceeded with the consenting procedures for the study and began the formal interview. As with each of the pregnant women, I began by asking her to tell me about her pregnancies. Her descriptions were vivid, detailed, and lengthy. In her descriptions, she gives a very normative account of her multiple preterm deliveries.

Illness Experience

Well, I might as well start from the first and head on down. The first one was a girl my pregnancy was wonderful. I didn't have any problems. It was just, I was 35 weeks . . . My baby was 5 pounds 15 ounces, good healthy, breathing on her own, I was worried because she was a preemie, that she would not be breathing, lungs and stuff not mature, but everything was perfect. She was perfect, a great child now, honor roll student, gorgeous, just beautiful.

*Second pregnancy, 2003, I was kind of upset with the hospital ...my water had broke, and I **knew** what I was talking about, but the doctor, she tried to tell me my water didn't break [and Precious was sent home]. I went back to the hospital about 6 o'clock, the lady say yeah, you have like absolutely no fluid just about, and she said we are going to have to give you some antibiotics, we are going to start pitocin because it could be possibly an infection around the baby. And, when I got ready to try to deliver him, he turnt breech, at that time, (snaps her fingers) stat C-Section, they cut me. I had a fever, the baby was fine, of course you know lung problems, because he was like 33 weeks. My pastor came and prayed. The same time the pastor was praying my son snatched the tube out his throat. They [left] it out because he was doing well. He been breathing on his own every since, except, you know, he has asthma.*

Next pregnancy was in 04, I sat in this same here room right here in this same spot for a month. This was like 11 months later. The two boys were 11 months apart. I had been in and out, I had a lot of trouble. Like with the last pregnancy, no trouble, I just like I said my water broke with the 2004 child, I was in the hospital right, but I wouldn't expect nothing different, I had just had a C-Section, you understand what I'm saying, my body wasn't really even healed. You understand what I am saying?

So . . . the last time I had went to the hospital was the day before Mother's Day. I had started having . . . a lot of serious problems, and you know I got to 5-6 centimeters and that did not move until [18 days later]. And the guy came in and he checked me and said your water bag's coming out first. I was 8 centimeters. I pushed him out, no complications from pushing him out. They took him over here right over to this NICU over here. And he was having trouble breathing . . . They threw him in the incubator, wrapped him up, he had to go through jaundice, and bili [hyperbilirubinemia] and they sent him home within the week, that baby passed away at seven weeks old of SIDS.

The next pregnancy it was fine, but I been pregnant too many times! I was very irritable with that child, and I couldn't be around pretty much anybody; the only person I could be around was my husband and my other two children . . . I didn't have no problems with her. The cord was wrapped around her neck. She was 34, almost 35 weeks. She was five pounds, one ounce, they said she was a great size for that age. Actually I took her home with me.

Next pregnancy I had some problems, I had started having seizures, um with this child at about, I want to say between 11 and 16 weeks I think it was, they gave me a cerclage, I carried that baby for 38 weeks! I was in and out of the hospital a lot, mostly because of the seizures, but sometimes because of her. I was contracting and dilating and everything. I delivered her 10 days before her due date, but the most trouble I had was in 2004, and this one right here.

In the descriptions given by Precious, she gave great detail about what occurred with each preterm labor and delivery experience. She also emphasized that despite the preterm deliveries, her children were “just fine”. She was proud of how quickly they were released from medical care, and she was able to take them home. She did not express any concern that there may be consequences, long term, for her children who were born early.

In the next section, Precious initially explains that she cannot understand why she has been delivering preterm, and says she did the right things to stay healthy. Then, however, she suggests she may have some physiological problem, or that she was responsible because she was doing too much, and had her children were born too close together. An interesting comment she makes is that rather than seeing herself as a source of risk, she considers it a blessing to have had the children. Precious explains that she believes her body reacts differently depending on whether she is carrying a boy or a girl.

Explanation of Causality

I have no idea, cause I took care of myself, I ate right. You know as a child my grandma told me that I wasn't even supposed to deliver, so I look at each and every one of my children, even Edwin who passed away, as a blessing. What happened was I had just started to have sexual intercourse, she had took me to have a pap smear, and birth control, and all this good stuff, and I guess they must have ran some tests that showed that it was going to be very hard for me to give birth. . . That's why I say that I believe that they are a blessing to me. But I don't understand they say that I have a weak uterus, and a tilted uterus, and you know, but with my girls, I don't have no problems, no really hard problems. I don't understand why.

And I really just started having trouble with him [patting her abdomen] and it seemed like my boys is what I have the most trouble with. I am not understanding why, but maybe that is how some women bodies is. Maybe some women can carry boys better than other women. Some people carry any sex good, but I haven't been that fortunate.

My boys though . . . I really don't know. For Paul I stayed on my feet a lot, that was my second child, 2003. I stayed on my feet a lot I had a one year old, I wasn't used to just, you know, sitting and Penny was getting ready to turn two and I had just gotten married so we actually were on the move and we weren't thinking nothing was going to happen . . . but just one day, I woke up and my water broke. And I don't know why, but it did.

To clarify her concept of causality, I asked her if she thought there was anything she could have done differently. In her hierarchy of responsibility as a mother, she opted to

do all the things she normally would with her two year old, and her infant who was having health problems, even though she was pregnant with another child. Although not strongly stated, there is a subtle implication that her baby 'still in diapers' prevented her from taking proper care of herself and may have indirectly been responsible for her preterm delivery. She recants her initial assertion that there was nothing she could have done about Edwin, but her ensuing conversation indicates that spacing still may have made difference.

Prevention

With Penny and Paul, there was nothing I coulda did to stop it, but Edwin, I probably could have. But the thing is, I am a stay at home mom, and when Edwin was born, my son was 11 months old. They were exactly 11 months apart. And, I'm up chasing my two year old daughter, and I had this baby that is still in diapers, bottle, he is still a baby, he don't know nothing, all he know is that I'm momma, he was born premature, but this was no small baby. He had asthma, and he was taking steroids, and I'm talking about a solid 6 months this boy looks about one years old, solid and heavy, my husband was working, I have no choice but to pick him up, he not about to get up and walk nowhere, he isn't walking, you understand what I'm saying?

But it's probably nothing I could have done about Edwin either, well what I coulda did was keep my legs closed, really and truly and waited until my body healed, but I didn't. And it was really nothing I could do about that situation, I had to carry him, I still had a two year old. Anyway there was nothing I coulda did about it. If there had been more space between the two of them, that might a made a LOT of difference.

Although these sound like contradictory statements, what she is saying is that once she became pregnant there was nothing she could have done to prevent the outcomes. However, if she had postponed becoming pregnant, allowing more space between her children, then perhaps the outcome would have been different. Precious expresses her belief that things are going fairly well with this current pregnancy, except that her seizures are not controlled, but leads into her discussion of how stress in her life is

impacting the fact that she is once again at risk for delivering early. The following portion of her narrative provides an explanation that directly implicates an incredibly stressed life.

Stress as a Causal Factor

It's stress that does it to me. The thing is still I have four children, my husband . . . gets up at 4 o'clock, he leaves at 5 o'clock in the morning, he comes home at 3 o'clock in the afternoon. I have to get my children up, two of them at 6:00 and you can't just get two of 'em up and let them two walk because the other two are about to get up and walk around. My two year old thinks that she's still a baby. Then on top of that I have to take care of my sister and my nephew.

I am in a stressful environment at this time . . . I'm 'bout to pull my lil' hairs out my head but you know it will send you into labor it will! The baby is part of you. The baby feels what you feel . . . The stress just it does it, cause when I start stressing I start contracting and feeling it all in my body so I know that it's bothering him he'll ball up in a knot you know when I'm stressed out . . . And as it [stress] kill you it will kill yo' baby I mean I hate to say it like that but it's true.

You understand what I'm saying, so I got a lot on my plate, you know what I'm saying? I get up, take my kids to school at 7:30 a.m., make sure they're fine, then come home, I make breakfast for the other two children, then . . . I feed my nephew, my sister upstairs sleep somewhere, he gotta eat, then 12:00 I gotta drop my sister off at school. Then I have to pick her up from school up at 2:15 then I gotta pick up my kids at 2:30 . . . I gotta come home, cook dinner, you know it doesn't stop. . . they just told me, you know, I might go home with bathroom restrictions only. . . It's nothing I can do, you can send me home with five bedpans, with a potty next to my bed, and I'm gonna move that thing over, I'm gonna go to the toilet like I been doing. My plate is always full.

As Precious enumerates her responsibilities to her family, she additionally gives an example of how, even while in the hospital, she is still trying to conduct household activities by phone. She concludes by observing that she will once again deliver prematurely with this pregnancy.

I had to get my children ready for church over the phone. My 8-year-old . . . I made her put the phone on speaker. My son is six, he is a young man, I've got to give to him. On weekends . . . he'll go downstairs on the line, they always got some clothes, somewhere, he'll get dressed . . . And he done washed up, brushed his teeth, brushed his hair, he feels good about his self . . . So I don't

have problems with him . . . And Penny, she's 8, of course she's getting herself together. . . she just started her flower, that's a grown woman, I mean it's sad to say, I cried about that . . . So I'm dealing with her hormones too she goes through some serious anger issues during that time. . .so like I said my plate is really full at all times. That's why I say give this baby maybe three or four weeks and he's gonna be out of here, like hello world!

Precious emphasizes in this statement the importance of her role as a mother and the standard that must be upheld in her home even when she is not around. She also explains that her eight year old just began menstruating, and that was stressful both for her daughter and for Precious. She was not willing to relinquish her responsibilities, but I inquired as to whether Precious had made any changes in her normal routines because she was pregnant. What emerges in this response is once again, her strong dedication to her children and their welfare regardless of what other challenges she is facing in her life. She said that while she may be better off in the hospital, she worries about her household.

I'm getting some rest, you know, more so like if I was at home, I would be at church running after the kids, so I feel safe as far as pregnancy issues in the hospital, but I would feel safer at home cause I could know what's going on in my household. Is my house clean, you know, who's at my house, you know. Who's around my children? What are they eating, cause my husband will feed them anything. I mean not anything, but he been done made some stuff that don't even go together. You know that have two different meals in one. You know, that kinda stuff. But I feel safe at home and I feel safe where I'm at, but far as pregnancy I feel at this point I feel like I'm safer here at this point right now today.

The conflict Precious is feeling is very evident. She acknowledges that her medical condition could be better addressed if she stays in the hospital, but she is anxious and worried about her home when she is not there. In talking about her sense of safety, I asked Precious if she believed she lived in a healthy neighborhood. She said it was okay, and that she was satisfied for the moment. However, by stating that there were no drive by shootings, she set a relatively low bar for what was acceptable to her.

Living Environment

It's quiet, I won't say it's the best neighborhood but I mean I don't even like Detroit. I was raised in [the suburbs] you know so I was kinda used to that city you understand. I mean it's older people that live around there. We probably about the youngest family on the block. So like I said it's not no drama on our street, so it's okay. I would rather go back to the suburbs personally cause that's me, I don't wanna raise my children in the city, 'specially the way that Detroit is.

My children going to school with all these things that be going on. My children have to walk through a metal detector to go to school! First grader and a third grader, they checking they books and wandng them even after the metal detector. You understand what I'm saying? Is they going to visit my daddy in jail or is they going to learn something? I rather for them to be safe than sorry but they shouldn't have to deal with that kind of environment.

I used to get up and walk the kids to school and my husband was like, "you know what I'm going to buy you, a van" . . . and he went out and bought the van . . . that's a little change that takes away a little stress from walking, to driving around the corner, you know because I don't trust anybody, because like two kids just got kilt at my kids school so I don't trust walking to school. So, if I have to go borrow some gas to put in my van I want to do that . . . I need my van to start up because I got two children I have to get to school . . . I already lost a child, I buried a son already. I cannot bury no more children. I will go crazy, literally. . .

Precious said she must protect her children, and she could not handle the death of another child. The high infant mortality rate in Detroit is directly related to the preterm birth rate, and death does not only occur because the neonate is immature. Sudden infant death syndrome (SIDS) is far more common in preterm infants than those born at term. The devastating and enduring impact the death of her child is shared in a manner that emphasizes what a critical issue preterm birth is for the African American family.

Oh that was hard, real, real hard. If it wasn't for my husband I wouldn't have been able to make it . . . My husband was there . . . but you [the mom] are completely bonded with this child. . . I always regret what happened, my husband was working, but I'm like we got 3 kids I'm 20 years old, I shouldn't have 3 kids at 20 years old but I needed to help him. When my Edwin turned 4 weeks, I immediately went to work. The day that Edwin had passed away, I just kept looking at him, and he sat inside that little car seat and he had smiled. He just had this peaceful spirit on him anyway.

This particular day my friend I am very close to, her grandfather had passed and the funeral was actually the same day that my baby had passed but I had called off, this how God works. I called off that Saturday for that Monday and we all kinda went to sleep. He was always on his same schedule go to sleep at 12 wake up at 5 for a bottle, go to sleep at 8. He was on a schedule and this particular morning I jumped up like "uuugh" I felt like I couldn't breathe. I had asthma issues but it didn't feel like asthma, I just felt like I couldn't breathe like somebody was taking my breath away from me or something, and my husband jump up like "Precious, are you okay"? He say okay, I'm bout to check on Edwin. My husband knocks on the door, he say "you know Precious you gotta rush to the hospital." I'm thinking that my son in there seizing or something. He say "Edwin's not breathing".

I threw my son in that car so fast, my husband did fly fast as that car could go like 120,130. . . . I took my son out, my husband grab the baby cause I just couldn't believe, I couldn't touch him. I'm in shock my own self. She grab him up out the seat, the lady, she say code blue and was pumping him and he was tryna come back. Something said, call your grandmomma, that's what made me leave that room. When the doctors was walking out the room with they head down . . . I say, grandma imma call you right back. They say, "we lost him" it was nothing I could do but just fall out right there in the middle of that hallway.

So he came, the doctor came to talk to me and my husband he say I can tell there is no foul play done to this baby. He say, this baby is completely healthy. He say this baby passed away but see, just looking at him he can tell, he say, but by it being a baby they gonna automatically do a medical exam at the medical examination thingy or whatever they do over there. He say, you know, that baby just passed away and his temperature was 37.3 36.3, they say that baby ain't even cold yet, meaning when I probably jumped up and couldn't breathe my baby might have died right then.

So they wrapped him up, I never touched Edwin again. . . I put my baby to sleep that night I gave him his bottle, I never touched him again. . . . They wrapped him up. . .she say, do you wanna hold him? I refused to hold him.

. . . his cause of death was sudden infant death syndrome, so we had to bury him. . . It just was sick that we had to bury a 7-week-old baby, that was the worst thing I had to do. I left my whole family and I can't believe I did that. I literally left my whole family. . . I would go out every night; I was so drunk . . . I was passed beyond drunk. I had start popping ecstasy pills, oh my God; it was just terrible, you know. . . I couldn't be in the house. If I go in my house I was going in my house taking a shower, changing my clothes..... Where's the next club at? . . .my next drink? It was crazy.

I probably didn't get myself back together until I realized I was pregnant with the 4 year old. I had to get myself together for her and for the family. I went home

and my husband and I worked things out and I been home every since, but that was a hard recovery. I was out of there for months; my son had just turned one, that didn't make no sense.

Precious withdrew from her family and turned to alcohol and other drugs to cope with the devastation of her loss. She took a year before she returned to her family to resume her role as a mother and a wife. She had to develop methods to celebrate Edwin's life, and not constantly mourn his death. I asked her if she blamed anyone. She blamed everyone.

Yeah I had blamed Women and Infants Hospital. . . my husband. . . my kids. . . I blamed everybody and it wasn't nobody to blame. It's just something that happened. . . it was like I have nothing, I wouldn't go to church, I wouldn't go to God for nothing. Only thing I was looking at was the liquor store. Just keeping it real you know. . . My kids, every time they seen me, I was drunk, just drunk.

In 2005 I got myself back together,. . .that was a hard thing for me to get over, it was really hard but now, you know, I used to go the grave site and thought I could dig him back up. I mean my mind was really gone . . .and I couldn't take the sight of seeing my son in the ground, . . . I really went through a lot of stuff, and my family, I also took them through a lot of stuff and they should not have had to went through that, but like I said things happen for a reason and I'm happy. I'm not gonna say I got over my son's death cause I didn't, you know it's still there but I have learned how to deal with it. Like on his birthdays what I do is I might cook dinner, you know, family come over we'll cut his cake . . . you know what I'm saying to still remember him. . .

Precious continued to grieve for her loss, but also found mechanisms to cope with this grief. She was initially unable to accept the help of her family but eventually overcame that emotional barrier. Families can offer critically needed support during pregnancy, but relationships can also be strained as a result of the illness experience with prematurity. Precious perceived tension in her marital relationship.

Yeah my relationship with my husband is affected because I'm in and out the hospital he's like I gotta work and most of my family is moved out of state, you know. His family they don't really wanna help but they try to help if they can. He might call me like I don't have a baby sitter, whining, then I might just go off on him like what is wrong with you? So, that kinda stuff, yeah. My grandma she

calls, she not gonna tell me she worried but she'll call my sister and tell her how worried she is. My sister of course gonna call me like "you know grandma called me, are you okay?"

In addition to the strain in her marriage, she acknowledges that her condition of being once again hospitalized for complications worries her grandmother, and this in turn worries Precious. As perception of risk can be impacted not only by personal experiences but by observation of the experience of others, especially family, I asked Precious if she knew of any family member who had experienced preterm labor or delivery.

I'll tell you how my family used to do. . .this is what my cousin used to say, "she just want attention. You can't really have no premature babies!" In this situation this girl delivered a baby last year, 1lbs 7oz baby, and I say God don't like ugly! The baby had to go through heart open-heart surgery, he had to go through double eye surgery he went through a lot of problems I'm happy to say he's doing well now, . . . My cousin tried to play me and talk about me like "her babies too big to be premature," and like I tried to explain to them dummies, it don't matter how big your baby, gestational age is what counts, and 33, 30, 34 those are not full term babies. . .she had that premature baby. . .I felt bad she had to go through the stuff. . .but sometimes you have to be taught a lesson, and learn from the lesson.

Precious judged that the reason her cousin had a very preterm baby was because she had not believed Precious was actually having preterm labor and delivering preterm infants. Precious believed this was God's way of punishing her cousin for not being understanding or supportive. Precious commented that she, herself, knew so much about preterm birth she could get a job on the antepartum high risk unit. I asked her about how she obtained the information she needed about high risk pregnancies. She stated she had a relative who had a very preterm infant, and she learned from that young woman. She said she learned from her own experiences, and from others. She also said her nurses on the unit were very helpful in providing her with information she

trusted. But, most of all, she said she knew her own body, that was what she trusted most.

Cause you have to go with your body. They have the degree, you understand what I'm saying, but a degree doesn't really mean too much . . . some things you have to know for yourself. Just like when I was pregnant with Edwin in this hospital. . . "Oh you're not gonna give birth for 2- 3 more weeks, but I delivered that day! I know my body! You understand what I'm saying? They took a test you might of heard of this test, fetal fibronectin, I had like 3 positive tests. "Oh, you're not gonna deliver." No, I'm going to deliver early! I know what I'm talking about ! So it's you have to be able to know yourself to trust yourself with that kind of information.

Discussion

The case study of Precious Perry exemplifies an explanatory model that identifies stress as the source of her pregnancy complications. She describes in extensive detail the factors that contribute to her stress and how she sees stress as leading to preterm birth. She said that "stress can kill you, and it can kill your baby!"

She notes that some of her behaviors, such as not properly spacing her children, and working too hard as a mother and homemaker, may have been possible factors in her pregnancy outcomes, but foregrounds stress as the primary contributor. Her perception of risk was tied to the stressors in her life. Having children preterm was normative for her, and she accepted that this would be the case with all of her pregnancies.

In a marked difference from the medical model, Precious asserts her own ability to construct risk, and frames the authoritative knowledge of her health care providers as only one source of knowledge, one to which she does not give privilege. Her long term exposure to the medical setting resulted in her use of medical terminology, and there were obvious semantic similarities between the descriptions she gave and what would

come from a medical professional. However, she was not always in agreement with her providers. Though ordered by her doctors, hospitalization was stressful, making it difficult for her to gain the benefit of relaxing her mind and her body. She preferred to be at home with her husband and children, attending to family matters, even though she was at high risk for delivering preterm.

Despite the complications she encountered, she counted each child as a blessing, particularly since she had once believed that she would not be able to have children. Referring to an unexpected pregnancy, she said, *“And it was really nothing I could do about that situation, I had to carry him . . . Anyway there was nothing I coulda did about it.”* The strong sense of maternal attachment felt by Precious is born out in research in African American culture, where pregnancies are valued regardless of life circumstances. Williams and Mackey describe this as the “strong pronatalist values in African American culture” that belie any other options other than to have their babies (Williams and Mackey 1999:36).

For Precious, the loss of her son Edwin was devastating. In 2001 Denise Côté-Arsenault and Mary-T. B. Dombeck published the article, “Maternal Assignment of Fetal Personhood to a Previous Pregnancy Loss: Relationship to Anxiety in the Current Pregnancy.” In this work they stated, “In American culture, the outcome of a wanted pregnancy is expected to be the birth of a live, healthy child. The failure to protect one’s child from harm attacks a parent’s sense of competence” (Côté-Arsenault and Dombeck 2001:652). In addition, they explained that the more the pregnancy is wanted, the greater the grief following the loss. The level of emotional investment of the mother was

a far greater predictor of the maternal response than the length of gestation. In this instance, her emotional investment was great.

Precious gives a heart-rending account of the death of her son, whom she said died of SIDS. Briefly, Sudden Infant Death Syndrome (SIDS), also known as cot or crib death, is defined as, “the sudden death of an infant under one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and a review of the clinical history” (Willinger et al. 1991:681). Precious was not sleeping with her son when the death occurred. While infant co-sleeping is vigorously discouraged in this country because of the risk of infant demise, a study by McKenna (1996) found that in countries where infant co-sleeping is routinely practiced, it offered positive benefits and a very low risk of sudden infant death. In the United States, however, SIDS occurs most commonly to African Americans, particularly if the infant is born preterm (McKenna 1996:205). This fact adds an additional level to the complexity of the process of assigning responsibility for untoward pregnancy outcomes, and adds an additional high level of stress, and distress to the mothers who deliver preterm.

Precious did not reflect on the presumed causes of Edwin’s death, but it was clear from her discussion that she suffered tremendously from the loss. She may have experienced conflict and guilt not only over the fact that she delivered prematurely, but also that her premature infant then died while in her care. The tragedy of his death profoundly impacted her life and her family. She did not understand why he died, but she thought she knew what precipitated his premature birth. While Precious believed

she understood the primary source of her risk for preterm delivery was stress, the next case study exemplifies a model where the explanation is unknown.

CHAPTER 9**CASE STUDY 3: RISK IS UNEXPLAINED**

“I would like to know why do I go through this all the time?”

I entered the room of Louise Latimer just after 2:00 pm. She was 30 years old, single, and had 2 daughters, ages 9 and 12. Her pregnancy was at 31 weeks gestation. I generally tried to avoid interrupting lunch, but in this case, Louise had not yet eaten. Louise was suffering from a severe form of “hyperemesis gravidarum” a condition characterized by excessive vomiting in pregnancy. By definition, it leads to the loss of 5 percent or more of the woman’s body weight. Hyperemesis gravidarum affects about one in every 300 pregnancies (emedicinehealth 2012). She sat up with great difficulty, appearing to be very weak. As I had watched her labor to sit up, I also saw an emesis basin nestled beside her.

Her short cut hair was standing up in erratic spikes on the top of her head and was flattened on one side, and if she had been laying in one position for a long time. Her hospital gown seemed to swallow her small frame, and the wide neck of the gown had fallen off her left shoulder, almost reaching her elbow. When I approached, I saw the lunch tray on her bedside stand, and she was trying to reach and pull the wheeled unit toward her. I introduced myself, we reviewed the study, and she signed the consent. She then made an immediate request. She extended the emesis basin to me, half filled with emesis, and asked me to dump it out quickly, before her nurse returned. She told me that if the nurse saw that she had thrown up again, she would not be allowed to eat her lunch, and she was starving. I explained that I was sorry, but I could not do that.

Having to refuse her request was unfortunate. I wanted to help her, not only because of my compassion for her plight, but also because I wanted her to feel comfortable with me and know that I cared about her. By sharing the conspiracy to hide the evidence, I might have initiated an immediate bond with Louise, but I would have committed an act which I knew, as a nurse, was the wrong thing to do. Despite the conflict I experienced between being an ethnographer and being a nurse, Louise accepted my apology gracefully.

She set the basin back down beside her and proceeded to pull the bedside stand in front of her. She placed her finger in the hole of the circular lid covering her plate and said, "I just have to eat something!" I brought her a soapy wash cloth and dry towel to clean her hands, and she reached for her sandwich on the tray. She had only taken two bites of the sandwich before she collapsed back on the bed. She told me we could proceed with the interview. It lasted 47 minutes. I began by asking her to tell me about her pregnancies.

Illness Experience

Louise's experience with prematurity extended beyond the problems of preterm labor, and she included in her description the problem of excessive vomiting that plagues her pregnancies. She saw this condition she was experiencing as normative.

I had both of my kids pretty early, around 7 to 8 months, basically 7 months. I was hyperemesis with both of my other kids and this baby is high risk and hyperemesis, where I couldn't keep my food down so it always end up where I have to have my kids early and they be under weight because I can't keep my food down that's how most of my pregnancies have been for the most part, I don't know, I just be sick the whole time.

Louise, who was 5 feet 4 inches tall, began her pregnancy weighing 125 pounds, and was down to 96 pounds on the day of the interview. Her doctors wrote that she

was dehydrated and severely malnourished. Her appearance was haunting with deep set eyes, ringed by darkened circles. She continued to explain the condition of this pregnancy, and as with Precious, questioned whether some of the complications she was experiencing were related to the gender of her fetus.

To me I was more sicker with this one. I don't know if it's because my other two was girls and this is a boy. . . My first 3 months was fine. Once I got to my 3rd month I been downhill every since, just sick non-stop. Of course I had to get the um, I have a PICC² line in my arm. I do my I.V. fluids and all my medicines that are supposed to keep me from being nauseated Reglan, Compazine [both anti-emetic drugs] and one more that they give me. . . they work most of the time.

Louise was able to manage her condition at home for a period of time with the assistance of a visiting nurse, but eventually, her condition deteriorated to the point that she could not be left alone.

So this is how I been having to go through my pregnancies. . .I have a nurse come out and they change this once a week . . .but basically I have been doing my medicines in my own home through my PICC line. I got to the point where I couldn't do stuff on my own I had got that ill and sick where I was weak, you know, from me not eating and . . .I got real bad off where I couldn't do for myself or my kids, I had to send my kids away where they could be taken care of elsewhere. . . I had to come out my own home . . . I had friends that would take me into their house and help me out. So I start feeling better when somebody can help feed me and stuff like that. That just all the stuff I been going through with this pregnancy.

Louise became completely dependent on the assistance of others, and recognized that she could not manage with this support. In the following discussion, speaks very positively of the condition of her unborn child, and the health of her other children who were born prematurely. Despite the many risks, she envisions only weight as a problem.

² A PICC line is an acronym for a peripherally inserted central catheter. It is a long, slender, small, flexible tube that is inserted into a peripheral vein, typically in the upper arm, and advanced until the catheter tip terminates in a large vein in the chest near the heart to obtain intravenous access.

So far the baby haven't had any problems, like any lung problems, the heart beats is always good and fine. . .He's always moving, on the move so he's projecting good, he's probably doing better than me in the inside. . . . it's just of course gonna be under weight. . . . He would have to be here to pick his weight up, so I'm hoping that's the only complication that he has. With my other two, they didn't have any complications or anything, that's the only thing they had to do was pick their weight up, so they did just fine. If you see them now you would never knew they was preemies or anything.

Louise emphasizes that her children look okay now (a sentiment echoed by both Stephanie and Precious), and as with the people in the study in Shivgarh Block, India (Darmstadt et al. 2008), she did not see the low birth weight alone as being a problem.

. . . They didn't have to be on any machines and incubators and all that stuff, they just basically had to stay to gain they weight. So I'm hoping that this baby be the same, you know, just need to pick his weight up. I hope he comes out with healthy lungs and no complications and problems, but so far they think everything should be straight from what they can hear from the lungs and the heart beat and everything and he been doing fine.

Louise, though, was at a loss to explain why she continued to have such serious problems with her pregnancies. She wanted answers that her doctors had not given her. She asks “what is it about my body that is making me go through this?”

I guess that I do have a pattern of high-risk pregnancies . . . first of all, why? I would like to know why do I go through this all the time? I never see too many people go through what I went through with my pregnancies. . . I don't know if it is the antibiotic that helped. I had the spits [excessive salivation]. . .with every pregnancy. The last 2- 3 days since they had me on the antibiotics I know I hadn't been spiting, which is a good thing, but it's like why do I got through this with every pregnancy, what is it about my body, what's making me go through this because this is not common, and every woman do not go through this. You do not see too many women that's that sick during they pregnancy and everybody else be up walking the malls and I'm always down and sick, and it's been with every pregnancy. So why do I have these patterns, high-risk, hyperemesis pregnancies, so I guess that would be the first thing I would want them to look and find out why do I go through this?

I probed further with Louise, asking her why did **she** think it was happening? Key to this case study is that she did not have an explanation.

I don't know, I always thought that maybe because I just always been a small person maybe I can't carry kids good, you know, cause I never been, outside of my pregnancy I'm a healthy person. I'm not sickly, I don't even really get colds. So it's like what is it about carrying a baby that sends my body through all this. I don't understand that at all cause I be just fine then after I have the baby I be just fine, but what I did notice was by me having them early, it probably would carry on the rest of the remaining months I would have carried them, but after that I be back to myself, I don't be sick any more.

There are many things to worry about when a woman is experiencing a second or third high risk pregnancy, and is very ill herself. In explaining what worried her, one of Louise's concerns was that she did not want a repeat cesarean section but was worried about what she had been told would be a "dry birth". The actual delivery process was a concern.

Right now my concern would be I'm hoping I do not have to have no c-section with this baby. I did have to have a cesarean with my first one and I had my second one naturally, so I'm hoping that I can have this one naturally with no problems. . . . so between the two of them those would be my worries, is the health of the baby and I do not want to have another c-section. Well okay, now I do have one thing, cause now this trips me out because my water broke, now to my knowledge when your water break that meant the baby was coming and they keep saying it's dry, a dry labor, and I'm like what is that, like how does that go? And I be a little concerned about no fluids being around my baby when I have it, now that's a concern.

She had already determined that her baby would be born early, that this was normative, and in her estimation there would not be any problems with the infant's health status as a result of being premature, other than needing to gain weight. While she said that she did not want to rush the birth, in the same statement she indicated that she actually did.

I can't keep track its 31 or 32 [weeks gestation]. Whatever it is that they need to do to get it out of here, I wish they could hurry up and get to it. I'm trying not to rush it because I know they trying to keep the baby in there for the baby sake to try to get more bigger or more nutrients or whatever, but I'm so ready for it to come out. Yes, I'm bed ridden until I deliver. Yep cause I'm bound to be here up to, they say I won't go past 3 weeks, it's the max if I don't have it on my own, then I guess they will do they part.

Louise's part, referred to earlier as the work of "keeping the baby in," (MacKinnon 2006) was to remain pregnant for the next three weeks. Then, the role of the health care providers ("they part") was to help the baby thrive once he was born.

The problems Louise experienced with her pregnancy also exacerbated the challenges she faced with her housing. Louise was living temporarily in an environment that was a major stressor in her life. The neighborhood was "rough", drug infested, and her car had been stolen. Her home was depressingly tiny. Because of her pregnancy related weakness, she had been unable to move to the new place she'd found. Neighborhood conditions are associated with poorer birth outcomes for African American women and Louise provided insight into the stress she was experiencing in her living environment.

Living Environment

I don't like the area at all, it's bad. . . it's a lot of drugs over in the area, drugs, crack heads in the area. I do not live like that, but I had went there temporarily . . . to have me and my girls somewhere to be for a minute and it was affordable for me at the time. Just the other week I came outside to take my kids to school, my car was gone. A couple of days before the car was gone . . .my stereo was gone. . .normally I can't even get up to go get my kids—I have to have my mother go pick them up, but I was feeling well enough this particular week to drive myself. . . I come outside on a Friday, the whole car was gone. . . so I'm really ready to go, but I already have a place lined up. I just been in the hospital so I can't make the moves to go get the lights and gas and go over there and clean the new house up and all that. Another thing I don't like about it, like I say due to the fact of my condition, it's a two family flat and I'm all the way upstairs. It's only a two bedroom. . . So after being there for so long and being sick in there it becomes depressing because you have nowhere to go but your bedroom. No living room, no dining room. . . I got a lil' table in the kitchen, so you have nowhere to sit but at the little table in the kitchen or your bedroom. . . so my kids was to the point where they didn't even like being there. I'm just ready to go from where I'm at and that situation.

Louise's seriously compromised health status made it almost impossible for her to care for herself without assistance. She stated that for the moment, home was not the best place for her, and she believed she was better off in the hospital.

Yeah, because like I ain't gotta worry about nobody fixing me nothing to eat or nothing like that. When I was home by myself I couldn't do nothing, you know. Or I feel safer when I'm around other people, when my friends took me in and was like let me get you out of here, come on over here with us . . . I start getting better because I had somebody that could help me, and I got so weak to the point where I couldn't even give myself my own medicine. . . My medicines had to be in the refrigerator and I had got that weak. I couldn't make it down the hall to the bathroom, I was using it off the side [she had a bedside commode] . . . because . . . I had got that bad at home by myself. So it was like yeah, I feel safer being at either in the hospital or just being around family and friends. Long as I'm not by myself.

Support

I asked Louise who takes care of her daughters while she is hospitalized, and Louise expressed great appreciation for the support given to her girls by her mother and their father. She explains the length they go through to make sure the needs of the girls are met. Interestingly, she did not seem to be aware that the issues and needs related to her pregnancies were stressful to her family, as was revealed in the interview with her mother.

. . . Actually it's my mother and their father. How it goes is, . . . I had to send my kids elsewhere because I couldn't get up to be taking them to school in the morning so I had to send them to their father. So they would go to school from over there, but he works so after . . . so my mother picks them up. After school she keeps them 'til he gets off work, then he get them when he get off work, he takes them home and start the pattern all over again. . . I don't know what I would do without them. . . I feel like I have lost my bond with my kids because . . . I couldn't get up and cook for 'em and get up and do they hair, you know, do the normal that I would be about to do. . . But for the most part things worked out to where they are being taken care of so where I don't have to worry about them. . . There is no way I would ever be able to repay them back for all this, I swear, because my mamma be on top of everything. She make sure she go to all the school programs . . . the stuff that I was doing for my girls, my mamma doing it

and it's a blessing cause a lot of people don't have that family support. So I can say it ain't nothing like having family.

In expanding the discussion of family support, Louise explained that the father of her two daughters was not the father for this current pregnancy. The father for this current pregnancy was imprisoned, and therefore is not available to be a support to her.

No, actually he just got locked up. That's another issue, but I don't let that get me down either. . . He go to court on the 3rd. hopefully. . . they just give him a year to 18 months. He done already served almost 3 months of that. If they give him time, we hoping that he only do like a year. We hoping that he only have to miss like a year of the baby life but it's gon' be hard for me to do this, like the beginning, on my own. Like, as of right now, I have nothing at all for the baby. . . no source of even getting it right now, but again I don't let that get me down because I say well maybe one day when I get out of here, maybe I could just have a baby shower and that would help. It's not like the baby will be coming straight home, so that give me time to get stuff together.

Again, Louise demonstrates in her discussion how normal it is for her to have a premature infant. She knows that she will not go home with the baby, so she will have to make preparations at home after she delivers, and is feeling better.

Family Relationships

The experience of premature labor and delivery, particularly when it occurs in multiple pregnancies, can have a negative impact on family relationships. For Louise, the impact was perceived as positive.

I wouldn't say that it affects in a negative way, if anything it brings you more together, cause actually my first daughter, I was kinda young, like 18, 19, me and my momma wasn't on the best of terms, me and my mother wasn't even speaking for a while. By me going through complications with my pregnancy brought me and her back together, where she bonded with me, and was there for me, and we got back on our level. So, if anything, I would say for the positive it would bring you more closer or something, than pushing you away.

I probed as to what she believed was the reason she and her mother had become distant from her during her late teens. As opposed to her pregnancy causing a strain on

the relationship with her mother, Louise thought that coping with the issues related to her complicated pregnancy made them closer.

I was young and wanted to be grown, and my momma wasn't buying it and so we fell off. . .but once I got pregnant and was going through my complications and things, she stepped right on in. . . that's what brought us back together, and she was right there, right there the whole time. Like I say I still was, well with one of my pregnancies, with my first one, I don't know how that went but my baby made it home before I did, probably because I had the c-section, but she came home before I did, I will tell you that, and she came home to my momma, to my momma and my daddy. They took turns with her because both of them were working so they would take turns getting the baby and she made it home to them before I did, so it brought us together.

Risk Perception

While a family history of preterm deliveries is a risk factor for preterm birth, the experience of witnessing this among family members can impact risk perception and explanatory models of risk. I asked Louise if she was aware of any family history of prematurity. She believed that she may have been born premature.

My lil' sister had no problems, just the regular, you know, from the beginning regular morning sickness, throwing up, but other than that she ain't have no problems. My other sister, she got two girls, no problems. I'm the only one. Actually I think I was a preemie, too, from my mother, I don't think she had any complications or problems but I do believe I was born early. Either I was, or I was just a lil' under weight, it was one or the other because I remember her saying the doctor made a joke saying she could have pooted me out (laughing) because I was so little so she could have just pooted me out.

Despite the fact that Louise was aware that her pregnancies were considered high risk, she stated that she did not think she should, in general, change her normal routine during pregnancy. She did, however, say that she needed to stop smoking. She admitted that her illness forced her to change her normal activities, because she was so sick, but the only activity she thought was risky was her smoking.

Well, for one I needed to stop smoking and that was something I hadn't been able to do during the pregnancy, so that didn't help. . .I didn't smoke cigarettes

like that with my girls . . .now because the more sicker I was . . .and I felt like if I throw up, a cigarette would relax me afterwards and take the nausea away or whatever. . .I didn't do that with my other one, so, I could say that's a difference cause that's gonna affect the birth weight of the baby. . . it's driving me crazy to be here but I actually wanted to be admitted in so I could not be smoking and stuff . . .I asked for the patch so I know that's a difference. I can't think of too much different that I did. I know that's one thing, the more cigarette smoke, and that affects the baby weight.

While not considering herself a risky person, she is aware that her health condition is a risk to her unborn child. She is at risk, and she is a risk to her baby. She utilizes her spiritual conviction or belief, however, that everything is going to be all right.

. . . I'm not really a risky person, I try to be safe and stay out of trouble as much as possible. . . I am the one that is always with kids. I got my two daughters and I always got somebody else kids. I'm normally the one that's always doing something with the kids or something of that nature. . . think positive. I don't think anything can go wrong, that's my mind frame. The only thing is the obvious, he's gonna be under weight . . .he gotta stay in the hospital to pick his weight up, that's how I wanna think. But the obvious is that there are risks and in the back of your mind, things can happen and I do kinda have myself braced and ready for it but I'm the type of mind frame that I can't think like that either. . .my mind is always on the positive, he just needs to pick his weight up, he gone be all right.

As pointed out next, Louise seems to have acquired her pregnancy related knowledge informally and randomly. She did not specifically seek information about her condition.

I looks through magazines, yeah, but I like the information channel, the baby channel. To me, they inform you about a lot of stuff, how to take care of the baby when you come home, then maybe complications that you might run into, and it tells you about a lot of illnesses and things and problems that you could probably run into. . . and I talk to my mom and my sisters all the time about what going on with me.

Louise believes she has a good relationship with the nurses on the unit and is happy with the care she receives. She particularly likes the supportive nature of the staff. However, she does not have a close relationship with any of the physicians, and is not sure which physician is her primary doctor.

I love most of my nurses. I guess the doctors are good but . . . I can't keep track with which one is actually my official doctor because doctors come in for this and that, other doctors come in for something totally different. (laughing) doctors coming in for my PICC line, you know, it's hard for me to really keep on post with who I'm dealing with. . . I'm known by my name like "Oh, Ms. Latimer is back!" with all the nurses. I know most of the nurses by name. I like that they come in and they talk with me, and they talk with me about the baby. They a big help, the nurses here, I love that. So overall I could say that I like being in Women and Infants Hospital, they do a pretty good job doing what they supposed to do and the nurses make you feel alright while you here.

Louise is aware that her mental state may affect her baby, and tries to be positive. In this response she does not acknowledge the depression or other stressors (e.g. the baby's father's incarceration) mentioned earlier. Like all respondents, she does not seem to be aware that African American women have a higher rate of preterm labor.

No, cause I'm not the type of person that really like let life get me down or stress about a lot of stuff. I refuse to let things stress me out because I know that will affect the baby . . . I just try to be positive.. . .If I'm stressed out all the time, I can only expect that it would be a lil' strenuous on the baby. . .Basically whatever my body is going through I know it is going to affect that baby. So I don't let myself get down, like even with the car being stolen. . . The thought of, okay, when I have this baby, now I gotta be thinking about how imma get down here to the hospital to be with my baby every day . . .I can't stress on it. It's been and done and it's over with and that's how I feel with most things. And most problems, I put it in the Lord's hands and that's all I can do. . . I'm dealing with enough that I don't need to be worrying about nothing. I'm already sick, why add on worrying about stuff?

Louise expressed a spiritual faith that whatever her problems were, the Lord would see to her needs. She said she did not need to add any stress to her life by worrying about things beyond her control. She did say however, that not being able to go church, and not having the physical endurance just to study the bible, was challenging her spiritual strength. She continued to assert, though, that she had faith in God, and that her mother was a tremendous source of strength and support. The interview with Louise's mother follows.

Mabel Hayes, Mother of Louise Latimer

This interview was conducted in the home of Mabel Hayes. She lived in a community of primarily brick bungalow homes. There were a large number of abandoned homes on her block, and the surrounding neighborhood was in poor condition. Although the home Mrs. Hayes lived in was also a brick bungalow, she had recently had her concrete porch and stairs replaced with new wooden porch, stairs and railings. I complimented her on the work, and she said she had just had it done. We stepped from the porch directly into a small, and very neat living room. There was an archway that led from the living room into the dining room, and then a doorway from the dining room to the kitchen. I was able to see directly into the kitchen during the interview. Louise's two daughters were doing homework at the kitchen table, and Mabel's husband was in the kitchen with them, apparently cooking. Mabel had an associate's degree in business management and was preparing to open a restaurant called "Sweet Mabelines." The interview began with her describing Louise's pregnancies, but the discussion flowed directly into the impact the pregnancies are having on the family related to the "vomiting" and "spitting" (hyperemesis and excessive salivation). Louise perceived her mother as stepping in to help in a warm and supportive way. She seemed oblivious to the full range of her family's concerns about, and reactions to her. Mrs. Hayes presented a very different point of view about the "closeness" created by Louise's difficulties.

Well, all of them [her pregnancies] are the same. . .the vomiting stage. . . . bent over and can't walk . . . spitting throughout the pregnancy. She lose weight, can't hold anything on her stomach so therefore she's not getting everything that she needs for the pregnancy.

And the spiting thing, that's what drives everybody crazy. . .It's like nobody want her around because she's constantly spiting . . . She's, it's like it's not a day that she really feel good, most of the time. Then she goes through a depression type thing . . . We try to tell her not to smoke cigarettes but she does. And a lot of things that she does that she shouldn't do, it makes us angry because you know you're not supposed to be doing this and you gotta think about the baby.

That really gets us, our family, her brothers and sister, upset but she gonna do her [be herself, from the colloquial phrase, I'm gonna do me]. It's like they don't want to be bothered with her, it's simple as that. She can ask them to do something and they'll say no, and maybe once the baby come they attitude might change.

There is frustration regarding Louise's behavior, a level of disgust because of the problem she has with spitting. The family is not happy. Neither the adults nor the children feel particularly charitable about Louise's pregnancy and the complications she is experiencing.

They [Louise's children] be very concerned. It gets to the point where they get so angry where they speak out themselves, and they say certain things. Like the oldest one, she'll say things like "my momma so hard headed, she know she not suppose to be doing things and she still doing it. . .you know what, I don't even care no more." Then I'm like, "Well Myah, don't say that. Maybe she'll get better"

She [Louise] was staying at her house by herself and she'll get angry because a lot of times no one would come over. But she had this nurse coming out quite often. But she be there by herself because they [brothers and sisters] don't wanna go over there, and not only that, they was angry because she got pregnant again. Knowing what happens when she gets pregnant and what she been through before, they attitude is like, "you did this to yourself, and you want everybody to feel sorry for you and be there for you, you did this to yourself!" But I still can't turn my back on her. That's still my daughter. Sometimes I get stubborn and get angry like, well I'm not gonna be bothered you know, but I can't do it.

Mabel says she cannot turn her back on her daughter, regardless of how disappointed she is in Louise. She knows Louise desperately needs help, and feels a duty to provide support.

I've been helping her the whole pregnancy. Yeah, the whole pregnancy, during the summer, and she be so sick and weak where she can't do anything for

herself, she just lay there. She has lost tremendously. I think its worst this time I would say than before with the other pregnancies.

Mrs. Hayes described the disappointment and distress she felt over her daughter's continuing health problems, and the fact that from her point of view, Louise did this to herself. According to her mother, Louise was responsible for her current situation. I asked Mrs. Hayes if she believed there was anything Louise could have done to prevent this.

Yeah, she should not get pregnant. (Laughing) but other than that, I don't think so. I feel like Louise, she has been small all the time. But I feel like her body is not really able to hold and carry a baby full term. She has had problems growing up. . . and I have taken her to many doctors and different hospitals and stuff but they couldn't say what it was.

Mrs. Hayes believes there may a physiological reason ("female problem") that her daughter continues to have complicated pregnancies, and describes a history of problems with Louise's reproductive system from the age of menarche.

When she first started having her cycle she had the same problem, basically the same thing, the vomiting, all balled over cramped over. But it was more than bad cramps . . . I can't remember the medical name that at one time this particular doctor had gave a name that he thought maybe is a possibility that it could have been, but I can't remember the name now it's been so long ago. It's like a female problem.

With the problems Louise was having, the solution Mrs. Hayes proposed was that Louise not get pregnant. She had some recollection that was a physical problem that predisposed her daughter to difficulties carrying a pregnancy, but did not know exactly what the condition was. On a scale from 1 to 10 with 10 being the highest risk and 1 being no risk at all, Mrs. Hayes rated the pregnancy risk for her daughter's health at a 10 and the pregnancy risk for the unborn child at a 10 also. I asked her to explain this rating and she described a frightening situation she encountered with her daughter.

Actually, I'm really scared for her actually. I'm scared because sometimes I feel like she might not make it or the baby might not make it. I been going to the hospital for these few days, this the best I've seen her look out of the whole pregnancy.

Well during the pregnancy I have been very scared and I have to pray a lot. I went over her house one day, I looked in her bed and I didn't see her. But she was in the bed with the cover on her. I had to walk over closer and look and pull the cover over. Have you seen when you don't make your bed up and it be all ruffed up. My poor daughter, she just looked helpless lying there. That's why it scare me so bad because I didn't think that she was gonna make it. She so weak and frail she can't even walk. Then she would say, "I'm so hungry", when she try to eat it comes back up. But right now I'm just so happy that she is so much better and looks so much better. It looked like she was so weak that she ready to leave us. So that was the scariest part for me just seeing her like that. Then she would always ask "momma pray for me". Then that makes me a lil' nervous.

. . . And then another thing really that concerns me too, is the baby and how the baby gon' be. Is that baby gonna be alright? You know, stuff like that.

When asked if she thought Louise was better off in the hospital she was adamant that the hospital was absolutely the best place for her.

Yes, yes. I have been said they should just keep her until she have the baby. . . . Not only that, see, she haven't been smoking and basically before Louise was looking like a crack head and this is the best that she has looked these past few days. My daughter was asking me last night when I came in from the hospital how she look, how she was doing, and I told her this is the best I seen her look even though her head jacked up but this the best I seen her look. (Laughing) I wish they would have put her in there and kept her sooner.

Louise's mother found comfort and peace of mind in knowing that Louise was hospitalized and receiving 24 hour monitoring and care. Mabel said she had not had any complications with her own pregnancies. She stated that all of her children were born full term, but said that she had one miscarriage. I asked her about what occurred, and she said it was her fault. She explained that she went to Cedar Point Amusement Park and got on some rides. When she returned home that evening she started bleeding, so she went to the hospital. Mabel said she was, "seven months along" and

that night she delivered a baby that weighed 5 lbs, 3 ounces. I inquired regarding this birth, because I was always interested in whether other family members, especially the patient's mother, had experiences with preterm birth. Although this was evidently a preterm birth, Mabel thought it was a miscarriage because the baby was stillborn. Of interest, also, was Louise's belief that she had been born preterm. There may have been a direct history of preterm birth in the family that was never acknowledged.

Discussion

The case study of Louise Latimer provides insight into an explanatory model that does not identify a source of risk. Simply put, her explanation is that there is no explanation. Unlike other pregnant informants, she does not blame herself, or a life that is filled with unmanageable stress, as the reason for her pregnancy complications.

Instead, Louise indicates clearly that she does not know why she is having problems. Although both she and mother alluded to a possible "female problem" this was not stated with conviction, or further explained. Louise also wondered if the fact that she was carrying a boy might have contributed to her being decidedly more sick with this baby than she had been with her two girls. Again, though, this was not her explanation for her overall complications.

Louise shared numerous aspects of her life that could be sources of great stress. She was too sick to care for herself, and was totally dependent on others for not only her own care but the care of her children. She regretted not being able to be the mother she ideally could be, and her daughters were becoming resentful and frustrated with her because of her poor health and dependence. Louise wanted to be a good mother, and envisioned herself as having been one, but now could not fulfill those

responsibilities. The father of her baby was in jail, and she had minimal financial resources, not even enough to buy necessary items for baby. Her car had been stolen, and that was one of the few material items of worth that she said she had. She saw herself as being very different from other women who were able to go through their pregnancies easily, without having their lives interrupted in any way. Yet, with all of these problems, Louise said she was not going to worry; she acknowledged her troubles but she was not going to let them upset her. Her faith sustained her.

While her perception of risk for herself was high, her perception of risk for the baby was minimal. Because of her experiences in the past, she was confident that even though the baby would be born early, he would just have to grow, and then he would be okay. The hyperemesis was so grueling that she was anxious to deliver in order to gain some relief, despite being preterm. She envisioned this as a safe trade-off, and did not express any knowledge regarding the long term consequences for children born too early.

Louise's mother did not share her daughter's confidence the baby would be okay, and feared for her daughter's life. She expressed frustration that Louise would put herself in this situation again, knowing how difficult her pregnancies had been in the past. This frustration was shared by Louise's sisters, brothers, and daughters. Though Louise had family support, she was straining relationships with the choices she had made.

One thing that Louise and her mother shared was the decision to remain strong in the face of serious adversity. Mrs. Hayes stated, "even though I say I try not to let things bother me with this pregnancy, it has bothered me. But I try not to show it. I gotta

show that *I'm still a thoroughbred*, I can't let them see that part." As part of a cultural norm, it was not acceptable to show weakness regardless of the challenges. Their positions were very much a reflection of Romero's *icon of the strong black woman*. While stressors abounded, they felt compelled to move forward without caving in under their weight. However, not acknowledging stress may not mitigate the intrusive and chronic physiological impact that ultimately is associated with preterm birth.

For Louise and her family, although the specific source of risk was not identified, the prevailing concept was that it was not an external factor, but resided with Louise.

CHAPTER 10

EXPLANATORY MODELS OF PROVIDERS

“I show my patients a lot of love, I show them that I care about them. I show them that they can call me, I’m gonna be there for you.” [Charlene Davison, CNM]

The providers varied in the manner in which they discussed women at risk for preterm birth, their explanations for adverse birth outcomes, and the role of the patient, family, and provider in this health challenge. Additionally, there were notable differences in the explanatory models based on the roles of the providers. The obstetrician, the perinatologist, and the certified nurse midwife—those practitioners who provided prenatal care and delivered babies—were closely aligned in certain aspects of their views, while the nurse and two medical assistants from the antepartum high risk unit shared key consistencies in their explanatory models.

In my conversations with providers I attempted to elicit explanatory models that were culturally informed, and not merely textbook explanations from the biomedical perspective. My intent was to examine the cultural categories that underlie the science and have them explain the concepts that informed their professional judgment. For physicians, there is a healing mandate, and of interest was how that mandate was approached when “healing” may not have been a realistic goal. It was important to understand how they discussed the limits of modern medicine and their expertise, and to ascertain where they placed responsibility for bad outcomes. I also examined what they considered a “good outcome” and the criteria they used for assigning this value judgment.

Providers were asked to compare their perceptions of risk with those of their patients and to discuss how they helped their patients grapple with uncertainty. If the

providers had authoritative knowledge that could be shared with their patients, knowledge that could prevent or at least decrease the likelihood of a subsequent preterm birth, how was that communicated to their patients?

Excerpts from transcripts are used in this chapter to illustrate both the convergences and divergences amongst the providers in how risk is constructed and explained. The topic headings are phrased in the form of a question, reflecting the manner in which the interviews were conducted, and are a broad representation of the summarized, more detailed questions and probes.

Carolyn Jones, MD

This interview took place at the hospital on a Saturday afternoon. Dr. Jones was the attending physician for labor and delivery. We had talked earlier in the day to arrange the time for the interview, but when I arrived at the hospital she was doing a delivery. I waited until she was finished, and she escorted me to the physician's call room, where the interview was conducted. Dr. Jones was a 42 year old African American woman who spoke strongly and passionately.

There were three very distinct repeating themes in Dr. Jones' narrative. First, she vigorously asserted that the relationship between the provider and the patient was all important, and an essential factor in promoting a positive outcome for the pregnancy. Second, and closely aligned to this theme was the staunch contention that prenatal care was poorly understood and poorly utilized by her patients, and that this impacted medical decision making and ultimately pregnancy outcomes. The third was that education was the greatest need to be addressed for the population she served. Tying these themes together was the concept that for patients, proper understanding and

integration into the health care system would yield improved outcomes. In this passage she lists common risks and expounds on the issue of prenatal care.

What are the Characteristics of a Woman at Risk for Preterm Delivery?

Malnutrition, smoking, late prenatal care. . . anything beyond 20 weeks, a history of preterm birth, a history of multiple pregnancies, substance use. What seems to stand out, and it might be a confounding factor, but what seems to stand out is a lack of education. Lack of prenatal care, definitely in the teenage population, and the younger population. And some of that is contributed to by the lack of access. A lot of patients I see, they say, well the reason I didn't get prenatal care I didn't have insurance, when I finally got insurance I couldn't find anyone that would take me, it took me a long time to get in. It might take them two or three months from initiation of thinking about trying to get prenatal care to actually finding themselves in my office. Maybe they looked up on the internet and they didn't find many places or many places were overcrowded and could not take them and that sometimes delays the care. Then, those that are multiparous get used to the fact that they had a normal pregnancy, their friend had a normal pregnancy, so therefore there is no urgency to receive prenatal care and then they will come later, the dates are off because you don't know if the baby is small for gestational age or if it is the actual gestational age by conception and therefore you may deliver a baby that is a lot smaller that could have potentially been preterm and by that I mean less than 37 weeks.

Taking into account the risk factors she enumerated, and the concern she had that women who come in late for prenatal care place themselves in a compromised position,

Dr. Jones related the evolution of a discussion about risk with a new patient.

I don't come right out and use the word risk, because I try not to focus on the negative in their pregnancy. What I talk about is nutrition, substance use, what do you do at home every day, are you active, are you working, are you in school, and I try to get an idea of what it's like to live like them. And then once I get into their world, then I identify risk. I say well you know if you do this you are at risk for this. . . Another way that I identify risk is to tell them about the different tests that we routinely do, and how they are at risk for those tests being abnormal. For example, if I have an obese patient, we start to talk about the fact that at 24 weeks we are going to check you for gestational diabetes, and I try to get them to understand what gestational diabetes means, how it affects them, how it can occur and what they can do to try to prevent it. So we'll talk about diet, exercise, their daily activities, and how we can get them involved early . . . so that maybe we can prevent the early onset of this disease in pregnancy. Well, let's see what we can do, don't listen to people when they tell you, take it easy, you're pregnant! I want you to move and do something every day. You want to go to the mall, go!

Walk the mall! What do you like to do? I then begin to start some pre-behavior modification. I give them permission to eat, but to eat healthy, permission to be active, permission to go to school, permission to continue to work, and get them excited about being active, because I don't want them to gain another 30 pounds. And on every visit I ask what did you do this week? You know that we are going to take that gestational diabetes test . . . What are you eating? Well let's talk about what ELSE you like to eat. And we talk about cooking, you know I try to keep it really basic and get into who they are. I talk to whomever comes to the visit with them. So it may seem simple, but if I put them in my shoes then they feel more empowered, and I have to put them in my shoes or they don't care. They have to care like I care.

In detailing her approach, it is evident that she both envisions and recognizes the push-back her patients will receive from others whose advice will be contrary to hers. While she is trying to promote dietary changes, and encourage exercise and an active lifestyle, she will be trying to contend with habits and beliefs in the community that could defeat her efforts. She uses the phrase "I give them permission . . ." which has a dual meaning. She gives them permission, first, to engage in the health promoting activities, and second, to respond to those who might disagree, by being able to say, "My doctor told me to do this."

Frederick Toma, MD

This interview was conducted in the office of the corporate chair of the department of obstetrics and gynecology of a major health care system in the region. Dr. Frederick Toma is a perinatologist recognized internationally for his work with fetal cord blood sampling in high risk pregnancies. He is African American and has spent his career caring for and treating women with very high risk conditions. The interview lasted 23 minutes.

Dr. Toma was very discursive regarding the factors that may place a woman at high risk for preterm delivery, but also conceded, repeatedly, that there was much that

remains unknown. His approach was a humble one, one in which he willingly admitted the limitations of his profession. The first risk factor he listed in this interview was *black race*.

I mean, risk factors: black race, white race and poor, black race and poor, a history of prematurity, extremes of weight, particularly low, the woman that is, starting off extremely thin, and or with poor nutrition, all of those are risk factors, I think. If I am going to try to make some sense out of it, I think the black race goes to some kind of genetic component and there are probably some identifiable genetic components. . . [research] in ruptured membranes showing that there are people that respond to bacteria or infection by elaborating enzymes that break down connective tissue quicker, so called MMP meta metallic proteases.

Elaborating on the concept that there may be a genetic component to the elevated risk for preterm birth among African Americans, Dr. Toma links genetics with nutrition.

Where the nutrition comes in—if you have a genetic predisposition for that kind of genetic based enzyme reaction—is having excellent nutrition. Does that decrease the risk of that genetic predisposition manifesting itself. I think it probably does. And just because you are of average weight does not mean that your nutrition is good. Are you getting enough vitamins and the proper nutrients you need? I think that probably cuts across racial lines, but if you put a genetic underlay on the problem in addition, that’s probably why black race is such a risk factor for prematurity.

Dr. Toma also acknowledges that improved socioeconomic status does not confer adequate protection for African American women.

*I do note that when you take educated black women and compare them to educated white women, as I recall it was a study done at Harvard, and this was probably over 20 years ago, there was still a fourfold increase in the risk in prematurity. And, the rate of prematurity with educated black women is less than it is for black women who are uneducated or of poorer socioeconomic status, but is still higher than for white women in the same situation. To me that is best explained by genetics, or **probably** best explained by genetics, because we don’t have an explanation for it. So I think that is where nutrition probably fits into it.*

Here Dr. Toma suggested disparities could be attributed to nutrition and genetics. He indicated that genetics would probably be the reason women in higher income brackets

still have a disproportionate rate of preterm birth. Next, his approach to discussing risk offered some frank insight into the fact that there is no known cure for preterm labor. In addition, he emphasized that while there are several tests that may show a woman is at increased risk to deliver early, there are few interventions available to help her.

I tell them that they have a high risk pregnancy and that the best that we can do is try to come up with some early warning strategies, that I can't predict that they are going to be the one, and that they may be, and that the sooner they are having some abnormalities the better [to institute the strategies]. Now when they are really, really at high risk, and it is kind of funny to say this because I am supposed to be an evidence-based practitioner but, unfortunately, the downside is because we don't have a cure, many of the things I do, like many doctors, are non-evidence based. For instance there is no real good evidence in the medical literature that bedrest is either curative or preventative for preterm labor but I certainly hand out prescriptions for bedrest all of the time.

The complexities surrounding the issue of confinement to bedrest will be addressed in the discussion chapter, but here Dr. Toma emphasizes the clinician's options for intervention are limited.

So I tell people that the more "off the feet" that they can be, probably the better it is, and in some cases there are some medical interventions, measuring the cervix on ultrasound, but again the cautionary pronouncement: that even though I may be able to pick up the fact that your cervix is getting shorter on ultrasound, and shortened cervix really is a risk factor for going into preterm labor, doesn't mean I can do anything about it. But at least if I see it shortening I may recommend that you stay off work, and that you stay off your feet. None of those things have been shown definitively to decrease the risk for preterm birth, but I really don't have anything else to offer. If I put a stitch in the cervix, that certainly hasn't been show to decrease premature birth and in fact there are complications that flow from having a stitch put in your cervix. So it is a very frustrating place to be in from a practitioner's point of view.

Dr. Toma admits to the limits of clinical science but in a later passage he shares an emic perspective that informs his care despite these objective limits.

Charlene Davison, CNM

Charlene Davison was a 49 year old African American certified nurse midwife (CNM). Certified nurse midwives are registered nurses who obtain a graduate degree in nurse-midwifery. Their focus is woman-centered care, and they provide prenatal, postpartum and gynecological care. They may attend deliveries in hospitals, birthing centers or in private homes. “Midwives are trained to care for normal healthy women during pregnancy and view pregnancy as a normal physiological stage in a woman’s life. They strive to help women have a healthy pregnancy and birth through education about their bodies and how to maximize their health during pregnancy. Midwifery care is focused on supporting what is normal, and minimizing unnecessary interventions” (Midwifery 2012).

This description, from a nurse midwifery website, aptly characterized the care given by Charlene. She worked in a school for pregnant teens and had a long history of being a strong proponent for the health care needs and rights of low income, disadvantaged women. She believed in empowering young women, but also worked hard as an advocate for pregnant African American teens, the primary population in her clinical practice. She was interviewed on a Sunday afternoon in the obstetrical triage unit of Women and Infants Hospital, during a respite following a chaotically busy morning. The factors she identified that place young women at risk were late care, infection, chronic health conditions, and mental and physical stressors, including working conditions. She also added concerns that the pregnancy interval is often too short, and that relationship problems may impact self-care.

I see the young ladies being at risk, and part of the reason is because they tend to hide their pregnancies for a long time so we don't necessarily detect

asymptomatic bladder infections or other infections they may have which can contribute to preterm labor—so the teen moms of course. And then those that have other complications, like chronic illness, the diabetics, the women with hypertension, and those types of things. I also think those that have excessive stressors in their lives, emotional, mental stressors, and I think those that have physical stress, whereas they work many hours you know switching shifts, those types of things, and they're on their feet a lot, like MacDonald's workers, and that type of thing. Often, they don't have the resources. You know a lot of times these kids are born so close together and her hemoglobin is low, she hasn't given her body a chance to recuperate. You know mentally, she may even have tried to have these children to try hold on to a relationship and it's just not there for her, she's depressed. So I think it wears on you, and I think it tends to show itself in signs and symptoms of preterm labor.

Charlene continued by addressing personal behaviors that increased risk. Smoking, and not using protection to prevent sexually transmitted infections were two major concerns.

*Also, dealing with them with this smoking thing . . . I think this is something else that we have that's high in our community, that we need to get away from. Marijuana, yeah, I see a lot of that in the urines, the marijuana, yeah. And then just exposing yourself. . . when somebody has given you a sexually transmitted infection and you're pregnant, then you need to think about that child. And our principal will just say, "Well, just go and write your **will** now because you certainly can get something that can take your life away. You're playing Russian Roulette with your body, and you won't be there, won't be available to your child," so, it's just trying to get them into reality.*

Nicole Greene, PCA

Nicole Greene, an African American, was a Patient Care Associate (PCA) on the Antepartum High Risk Unit at Women and Infants Hospital. Nicole was formally trained as Medical Assistant and then went on to complete certification as a PCA once she was hired at WIH. She had worked on the antepartum high risk Unit for 12 years, during which time she had also been a patient. She delivered an infant at 28 weeks gestation, following hospitalization for two weeks for preterm prelabor rupture of membranes (pPROM). While Nicole noted that there did not seem to be any striking characteristics

that identified women who would be at risk for preterm delivery, she did see a serious problem with the women who were drug addicted. She concludes this passage by making a comparison between the drug-addicted mother at risk for preterm birth and the non-addicted mom.

Well actually, nowadays, it seems like everybody at risk, because the young ones come in and they have so many complications, and you know, short cervix, they just have all kinds of things going on and you know we have some of our patients that are older and they've had problems. I had one, she had 12 losses and this one is the furthest she's went, she's like 28 weeks now, so we're hoping that that one survives, so she's had a hard time. So it just varies, it's all ages. It's no certain race or it's like a little bit of all of them. You just see it so often now. . .we do have some moms who are crack addicted, mostly crack addicted, we have some heroin and theirs don't do so well, even at term, because they have so many problems.

Nicole continues by describing what babies who are born to drug addicted mothers experience.

They used to give the babies the methadone but they were doing some studies and they said that the methadone long term wasn't good for the babies so now they give them morphine, but it's harder to wean them off the morphine, than it was the methadone. You know these babies had been there [the nursery] like for months and they couldn't send them out because they couldn't wean them off the morphine, so it's sad because they just cry, they don't sleep, they're always just so agitated. . .

Nicole's conclusion is that the mothers with substance abuse problems just do not care.

You know, they don't care as much, so pretty much they just do whatever, they sign themselves out, they pretty much don't care about their care, but the ones that really want their babies you know they'll be compliant to their bedrest and you know just follow what they supposed to do whereas they [drug addicted moms] pretty much do what they want to do and don't really care. Most of those patients don't really want to talk much, because they are like in an uproar, they're angry because they're here, they can't get high, and they really don't want to be here, they're usually a tough patient. Some of them you can kind of talk to but some of them are so far gone that they just don't care what you say and it just doesn't matter.

As Nicole frames this, the babies suffer mightily when they are born addicted, and their mothers don't care. Nicole's evident frustration with mothers who were addicted, and who were not willing to listen to care providers is contrasted with the assistance she provides to mothers whom she views as being open to receiving help.

Because of her experience of having given birth to a premature infant, Nicole was sometimes asked to talk with newly hospitalized patients on the high risk unit who were distraught over the prospect of delivering a baby preterm. Nicole was very sympathetic to the anxiety these women felt, and offered practical and supportive advice to them. In the following passage, she not only shared how she felt during her own experience, but highlighted what an ordeal women must go through. Her advice about how the neonatologists should talk with women raises the issue of how these physicians sometimes must walk the line between informing women of some of the grim realities of prematurity, while still offering hope to the expectant mother. As will be discussed later, some providers believed there was great value in having a positive outlook.

Well they'll usually ask me like how far along was I, how long was the baby in the [neonatal intensive care] nursery and you know I tell them it's not an easy place to be in a nursery so you will have some stressful days you know, you'll go up and down. You have 10 good days but that one bad day will wipe out all your good days. You'll just be on an emotional roller coaster but you just have to stay strong and just be there every day to see about your baby and before you know it, it will be over. And, it seems like you're never going to get there, but I say you do.

And it gives some of them hope. Because you know when they come in and have the consult from neonatal they [the neonatologists] say your baby will probably be retarded. You know how they tell you all the bad things that can happen, and so you know, usually when they leave out the mom is crying because she is all upset now cause she's thinking this is going to happen, that is going to happen. I said, but you know, they don't really know what's going to happen, you just have to wait and see, just be there for your baby's care and ask questions.

When I was going to deliver at 27 weeks they said all the same things, that she would probably be retarded, she probably won't make it, even after I had her, you know like it's just going to be day to day, she's little, she's sick, she may die overnight it's kind of a cold feeling over there [neonatal intensive care nursery], but I just stayed positive and I prayed about it, well the doctor doesn't have the last say . . . I mean that's fine, but then they should give you like the other fold, or tell you a success story or something to kind of cushion that blow, but the one doctor said, well you know the good thing is they say African American girls, when they are preemies, they strive harder and they usually do good when they're preemies so that was the only positive thing that I got out of it.

The reason why is, I guess as women we have to strive so hard, we have to take care of our kids, we have to do what we have to do so, I guess as babies she said that they've done plenty of studies and she said that the girls do better. The African American race does best you know, the females they strive, they fight hard, yeah they fight really hard.

Nicole's statements reflect the concept of the "Sojourner Syndrome" described earlier. She says that the female African American neonate fights so hard for survival because, as a woman, she will have to fight hard for survival. While talking about women desperate to save their unborn children, she segues into a discussion of how some women significantly and perhaps intentionally increase the odds that they will deliver prematurely.

Some of the other ones, they'll do something, you know get up and do silly things and then, you know, the cervix is short and they'll keep walking, trying to put stress on it so they can deliver, and a lot of them want to deliver when they come in. They're 27 weeks, they don't mind, they want to deliver. "I just want this to be over so I can go home!" They don't think long term about the baby. They don't even think that far, they are thinking about themselves, and they want to go home. It's not really about the baby all the time, it's about the moms. You know they get with these men and they get pregnant and then after the men don't want to be bothered with them anymore, then they don't want the baby. Just like the men don't want to be bothered, they don't either.

Denise Fields, RN

Denise Fields was a registered nurse, holding both a bachelor's and a master's degree in nursing. In addition to 28 years experience working on the antepartum high

risk unit, she also had been teaching nursing at two local universities for the past 12 years. Denise, an African American, had no children. She took a hard line regarding personal responsibility for the women for whom she cared. Similar to her co-worker Nicole, she also did not correlate any specific characteristics that would increase a woman's risk for preterm delivery but saw poverty as a possible explanation for the large number of woman at her institution who delivered prematurely.

I don't know if there is a specific type that I can identify, because we get patients of all kinds, white, black, young, old, first baby, not their first baby. You know most of our clientele are African American, and many of them are on assistance, so I think that may make us a little more biased, but some are educated, some are not educated, you know. I mean I see why they haven't been able to find out what's going on because it doesn't seem to be one particular thing or one characteristic that they all have. I'd say there are more in the poor category but then again, it's the hospital that we're at. If I was out in [the affluent suburbs] or something, I don't know if it would be the same because they probably don't get those patients on ADC and welfare, cause they're coming down here. The patients are more likely to be educated, with a job, and probably more non-blacks.

Expressing some pessimism about the influence her teaching would have on patients at risk, Denise did state that she reviews some basic information regarding the pregnancy and recognizes the challenge many patients face in trying to maintain bedrest.

I might talk to them, that there's an increased chance of preterm with subsequent births, that they have to make sure they get the prenatal care, that they have the rest and they have the support at home to help them. They need to be on bedrest, can you be at home on bedrest? Cause we do get some patients that keep here because they need to be on bedrest because they've got four other children at home and if they're at home they have to take care of them. So we run into that a lot. So they will keep the patient because of their situation it is not conducive to them getting rest.

What is the role of the provider?

Central to the discussion of how patients and their providers explain risk, is a description of the self-perceived role of each of these actors. By elucidating how each

role is perceived, valuable insight is gained into their personal appraisals of causality and responsibility in this matter.

Dr. Jones emphasizes the importance of getting to know the world of her patients. In this extended excerpt on her role as a provider, her discussion covers the manner in which she interacts with her patients, how she changes the attitude of a patient who sees preterm delivery as normative, the way she attempts to educate patients on how to use the health care system, and how she engenders trust so that patients know they can rely on her presence and expertise.

Carolyn Jones, MD

I get to know the person, and as I get to know the person then I try to tailor my care based on that. If I don't understand your world, how can I communicate with you? Then everything I say is kind of "cook-book routine," I can't get any kind of compliance or cooperation in your care if you don't know what I'm saying, and I don't know what you're saying. It's just not going to happen. I have it happen all the time, I have patients say to me, "Dr. Jones, wow, this is really neat", and they get really excited and they are like, "I feel like I can relate to you, I feel like I can talk to you". They are comfortable asking me the questions, because they know I am not just going to blow them off because I need to get to the next patient. That's important. And they open up and the more I appear willing, the more engaged they are. That is so important, but they don't have that.

Among the myriad problems poor African American women face is the problem of a health care system that is not responsive to their needs. Dr. Jones addresses how she believes the interaction between provider and patient should be conducted.

If I suspected that she was high risk a lot of times I kind of get an idea of what their perception is of what their prenatal care would include, and then I start to educate them about what it typically should look like, what they have missed so that they feel the urgency that I feel. I make sure that there is some tight communication between the two of us—seeing if they have received this unofficial, hit or miss prenatal care, from different urgent care centers, different clinics. "How many times have you been to the ER?" Different things like that.

A lot of us just show up at the hospital, and I noticed that even when I was in residency, and even now we just show up at whatever hospital and there's no

connection with the doctor, “who’s your doctor?” “uh, uh I can’t think of the name you know he’s over there on this street or that street” you know, there’s this disconnect so you come in and the provider is forced to make decisions based on the history the patient gives, and trying to avoid a bad outcome by making a decision and trying to do what they can at that time. So if you come in and your blood pressure is out the ceiling, and I have no idea how someone’s treating you, I just might induce you, and not let you go anywhere. I am going to try to protect that baby.

For example, I have a patient right now, she’s late prenatal care she’s used to having preterm deliveries. Well, she usually shows up somewhere, her blood pressure is high, and they induce her and that’s it. Well, she came to me, I made sure I had very tight dates with her [firm establishment of gestational age], very close contact. She had issues with understanding that prenatal care is not just see the doctor, get an ultrasound and wait to go into labor one day. So what she said to me, well usually when my blood pressure goes up it’s time for me to have the baby. So she showed up in the triage and she just knew she was going to have this baby, and I said, no, but Dr. Jones but it’s time to deliver me, I’m ready. I said, no, the baby is 32 weeks. Well what was your biggest baby, five pounds, two of them were preterm, and all the rest were induced due to some type of hypertension and sugar. I said not this baby, and she went home.

She had kind of accepted that all babies would be preterm. She is approaching 36 weeks now, I have her on blood pressure medication, her ultrasound is great, her non-stress tests are great, I told her we are going to have a 9 pound baby this time. So now I am starting to hear these complaints about being tired of being pregnant, and getting bigger, she’s never been this big, she’s never made it this far.

But, with the initiative of taking the time to interact and getting to know her both medically and socially we’ve been able to keep this baby inside for a little while longer. She’s doing well, and now she doesn’t panic. And now she’s able to identify with her symptoms, identify if she’s having any kind of anything strange and she’s getting to know her body better, and know how to communicate with me openly so that we can have a healthy outcome. So that’s probably a very good example, where every single child has been preterm.

For high risk patients, Dr. Toma’s describes his role as first to assess his patient’s basic needs. From there he makes sure that these women know the signs and symptoms of preterm labor. For his African American patients he does inform them of their elevated risk, and comments in the narrative that not being married also increases their risk of delivering early.

Frederick Toma, MD

I think that my early concerns are trying to figure out whether or not she has enough to eat, and if she is in a safe environment. I happen to really ask those questions. And then my focus is on letting her know that she is at risk and making her aware of the possible signs and symptoms of premature labor and premature birth, and premature rupture of the membrane etcetera, . . .and encouraging her to not to wait and let these symptoms carry on for days but to go and get help immediately.

Does ethnicity make a difference in how I counsel women? Not really except that I probably would tell them that as black woman your chances of having a premature baby are higher. But I see plenty of white women who aren't married too (laughs). You know, it doesn't impact them. So I'm not telling all of the black women go get a man and a preacher. And obviously there is higher rate of out of wedlock kids in our community. I think most recently the census said 78 percent of all African American kids are born out of wedlock in the United States.

Dr. Toma may appear to be making a very strong moral statement when he is discussing marriage, but married women in this country do have a statistically significant lower rate of preterm birth. He did not address the moral aspects of the issue. While Dr. Toma structures his role around teaching, Charlene constructs her role around the issue of support. She indicates that it becomes all important for those who lack this vital resource.

Charlene Davison, CNM

I think we need to get back to the support. I think that supportively we need to take our people out of toxic situations, and away from toxic people, and I think that during pregnancy, we need to put them in as supportive an environment as possible. I know that in Cuba they have these places where after a woman gets so far in a pregnancy she comes and lives at the place where she's nurtured and taken care of and I think in some cases that is what our people need to do.

You know I can remember being at the school and one of the students started bleeding profusely. Fortunately she came to me and said I'm bleeding, I'm bleeding, so we took her in and she had abrupted [placental abruption] so they delivered her. I called her aunt, and asked her to meet us here at the hospital but I saw nobody. So they have access to Women and Infants' Hospital by having access to me cause I'm gonna get them in here and get them to where they need to be. I think it is good for them to have people in their life that can penetrate the system and where they feel like wherever their needs, they are not falling on deaf

ears. What I am saying is that they don't always have the support, you know, and they need that, so we need to be able to validate them and what their concerns are, as well as just give them the supports that they need, nutritionally, rest wise, keeping them focused academically, you know.

Next, Charlene responds to the question of whether a patient's ethnicity impacts care. She explains that her young African American patients often do have extra needs and health risks, and her awareness of this fact does affect the care she provides.

I can hardly do an interview with an African American young woman and her mother doesn't have hypertension. So it's like we look at all that. Even if they have gestational diabetes then I talk to them about the importance of maintaining your weight, getting into some exercise program, you know.

*I want to show my patients, I show my patients a lot of love, I show them that I care about them. I show them that they can call me, I'm gonna be there for you. I talk to them very bluntly about coming in here repeatedly with sexually transmitted infections. I talk about not having sex with him because he does not deserve you! Those are the kinds of hard things that I talk to them about and I embrace them in ways that I think, just to let them know that I really care about you and I try to give them the standard of care that is **A-1!** I try to do everything that I am supposed to do for them, when I am supposed to do it.*

Charlene indicates that the care she offers not only considers clinical diagnoses, but addresses psychosocial needs, born out of her cultural understanding of a problem she regularly deals with as a clinician. The support and sensitivity with which she delivers her services, and her availability and openness, are critical aspects of how she believes her role can impact birth outcomes.

Nicole Greene, PCA

Nicole's culturally informed experiences helped to shape her health care role and her communication with the patients on her unit. She intimates, as do other providers, that a woman's fierce commitment to a healthy outcome can make a difference in the life of her unborn child.

And then a lot of nurses will tell the patient, like “she [Nicole] had a preterm baby” so you know they’ll want me to come in, they’ll ask me a bunch of questions, especially the women who had a lot of loss you know, so they’ll want to know what my outcome is, you know because they’re depressed especially if they multiple loss, you know they’re afraid of what may happen again. Yes, and I tell them I say well it’s for the baby [bedrest] and I try to take them like crossword puzzles and you know I go to the dollar store and I buy them different little things that they keep themselves occupied where they can keep their mind off of it, kind of. Some days it’s good for them and some days they don’t want to be bothered. But the ones that really, really want their babies they don’t change, they’re the same every day. Like my patient now, you would never know she’s a nurse, her husband is a doctor, and she’s just a regular patient and whatever you have to do for her, you know, whatever she needs to do, she wants her babies, she’s just trying to work hard to stay pregnant.

How do you Explain the Disparities in Birth Outcomes?

Black-white disparities in birth outcomes have never been fully elucidated, so the responses from African American providers on this subject add a component of insight not available in the literature. Dr. Jones continued to construct risk primarily around the circumstances of the lives of her patients who grew up in poverty, in disadvantaged communities that lacked basic resources and offered poor educational opportunities. When asked why African American women of middle income also had such disparate outcomes, she gave an explanation very similar the concept of weathering introduced by Geronimus.

Carolyn Jones, MD

Well socio-economically you got to look at the inner city, you’ve got to look at, you know, the socioeconomic factors and the issues with the school system and all that. And then if you take these certain mindsets, that dictate behavior, and then that behavior dictates the increased risk. I look at it from a holistic perspective, because all day long I can bring in nutritionists and do all those things, but with younger people what will dictate what they do is what’s going on in the community. With teenagers they are probably at increased risk because more socioeconomic issues occur. I think it is a host of factors.

Now when we talk about that well established, educated, African American woman, we have to talk about how old she is. Age plays a role as African

American women develop chronic conditions earlier, so those same health risks affect the pregnancy. Maybe the Caucasian population may not suffer with the hypertension at 40, because their cardiovascular system may be genetically different or just throughout time just didn't evolve to have those types of risks, whereas ours does, and you put us somewhere between early 30's, mid 30's at an advanced maternal age, then we would just be more prone because we already have a predisposition that would then contribute to those medical problems. You can take out the financial situation, the education situation, you can have the healthiest habits and still be at risk because you are going to be a risk for those things anyway. And then you put your body in that compromised medical condition of pregnancy, and you know pregnancy being a stressor anyway, and those problems just manifest. How many people do you know who once they have been diagnosed with gestational diabetes then they keep diabetes; diagnosed with gestational hypertension and preeclampsia, then keep hypertension? You are going to be at more risk anyway at an older age, but that is just adding more predisposition, you are just going to get it sooner or you are just going to have those medical complications in pregnancy a little more than the Caucasians in similar situations.

Explaining that African American women are not only more likely to develop chronic conditions but that they develop them at a much younger age than their white counterparts, Dr. Jones presents a theory that the addition of the “compromised medical condition of pregnancy” exacerbates any predisposition to disease.

Frederick Toma, MD

In discussing why there are disparities, Dr. Toma says a considerable amount, linking causality to environment and culture. His response draws connections between racism and its impact on living conditions, and life chances, and how that is ultimately associated with preterm birth.

Oh, I think good old fashioned American racism has something to do with it. It may not have a lot to do with it directly in that black women, I don't believe they are being barred from prenatal care. Quite the contrary there's a lot of opportunities for prenatal care. So why scream racism? Well, what leads up to the educational disparity? Does any of that have to do with racism? I do believe that here isn't as much concern about really doing something to increase the education levels. Does job discrimination play a part? And, does a lack of education . . . that I do think has something to do with racism in this country . . . does a lack of education, which begets a lack of job readiness, which begets a

lack of getting a decent job, which begets a lack of being able to live in a decent neighborhood, have a decent income, move into a more decent neighborhood with decent schools. Yes, I do think that racism has something to do with it. Do I think it has everything to do with it? No. I think that in addition to racism I think that there are some issues of lack of taking responsibility for situations.

*I do think that it's become, well it has become more than the norm in our community as African Americans to have kids out of wedlock. And unfortunately, kids without two parents are at a much higher risk of poverty. We know how to prevent pregnancy but women are either not caring or in many, many situations women are making a conscious decision to have babies without a husband around or a man around who is going to be very involved with those kids. So how does that relate to prematurity? Well those kids are in poverty and poverty is related to prematurity. While we are talking about poverty and contraception—we know that if a woman gets pregnant within 18 months to two years of a first pregnancy or previous pregnancy, if the inter-pregnancy interval is shorter **and** she has all of these socioeconomic limitations going on, then the risk of prematurity is much higher. So, I guess the bottom line answer to your question is that I don't think racism is all of it but I do think it plays part in health disparity and prematurity.*

Although he recognizes issues related to personal responsibility, Dr. Toma conceptualizes racism as the factor that creates and perpetuates a cycle of poverty. He also associates poverty with the short interpregnancy interval, which can impact preterm labor and delivery.

Charlene Davison, CNM

Charlene's initial response to how she explains disparities correlates with the fetal programming concept introduced by David Barker and associates in 1990. She sees disparities as the outcome of disadvantages that began at conception. Her comprehension of the community or macro level impact of discrimination is evident in her description. She makes a distinction between income and wealth when addressing why middle class African American women remain deeply affected by preterm birth. She also expresses concern about a breakdown in the African American family unit.

I think we kind of start out in the womb at a disadvantage nutritionally, just the supports and you know, and I think it plays itself throughout our lives, and I think you can almost stereotype and see certain people if they're going to breast feed or not, you know what are they doing to support this kid, to support this pregnancy, to support themselves, you know, it's just we have a disproportionate amount, it seems like everything that's negative, it hits us harder.

I don't think we have generations and generations of wealth, I think like even with myself I probably make over a hundred thousand a year, but take care of so many people with that money. So that's probably what . . . even when we do get a notch out, we are still plagued with all the disparity around us. So, that's what I think plays a part in that. You know, I think as we live our lives we are just so inundated with so many adversities, even when we manage to get ourselves out, everyone else around us is still drowning. So you know we spend a lot of time trying to deal with that. And you know I think that wears on us. I think we are in a position where I think the families have broken down. Like I don't think the Hispanic rate is as high as ours, and I think their families are still intact. Although they may not be socially, economically in a position better than we are, but I think they still have that support of that family which I think is very important.

Concern about nutrition is a theme frequently revisited by Charlene. Her concern is directed toward the lack of ready resources for healthy foods in the community, and her patients' lack of exposure to eating nutritious meals.

Nutritionally, knowing that we don't even have a grocery store chain in the city of Detroit, these are some of the things we really need to look at. We had a conference the other day at the school where we were teaching the students to eat healthy snacks for cheap, and they turn up their nose at fresh fruits and vegetables and lettuce and those types of things. We need to retrain ourselves from the very beginning and carrying out through life what is healthy, what is healthy eating, you know, healthy living, taking in substances, marijuana, cigarettes, how does that affect your health, how does that affect the health of your child. Getting them to see the connection, the correlation between asthma and different things and really their whole lifestyle and the changes we that need to make as a people. But I think you know when we have generations and generations of poor eating habits, it gets into you genetically, it can alter and change your whole disposition and the family's disposition.

Following with the concept that there may be a genetic component that explains why women of higher SES have so many preterm infants, Nicole gives examples of why she believes this to be true.

Nicole Greene, PCA

I think some people it's just a genetic thing and everybody has it, like one of our nurses, all of her babies were preterm, all her babies, she never went full term with any of her babies. Some women it just hits 'em like the one we have now, she's just a short cervix and just every time, every time it's just the same thing.

I would say education and income don't make a difference with ours [African Americans], because it's been both ways, 'cause even our nurse anesthetist was here and her husband is a doctor, and she still had preterm problems and I just think sometimes it's like a genetic thing and it kind of trickles down.

Vivica Westmoreland, PCA

Vivica was a PCA on the antepartum high risk unit. All three of her children had been born preterm. Her last child was conceived through In-Vitro Fertilization (IVF) and she believed the toll on her body from the IVF procedures was the reason that this child was born preterm. Vivica, a 41 year old African American, had worked on the antepartum high risk unit for eight years. We conducted the interview in the break room on the unit. Her explanation for disparities in birth outcomes begins with nutrition, but she also implicates stress, income, and lack of proper prenatal care.

I think the way we eat. You know when you're younger, when you're growing up, you eat what you can afford. And I can admit it, we used to have a lot of fatty food in our diet, and in the long run that causes you to have high blood pressure, which we see a lot here with our patients. High blood pressure, it's scary. Serious high blood pressure, it's scary. And some of them you a look at them and wow, they're young but . . . it's got a lot to do with our diet. And stress, whether it's emotional, financial, things that are going on in their lives, like they have stability as far as home life or something like that. And, income, yes because if they don't have health insurance, they don't come to the doctor. They don't get the health care they need. As far as taking their prenatal vitamins, going to an OB doctor, just having a regular check up with the baby—because that really is an important factor in being pregnant. . .getting the care that you need, you and the baby.

Denise Fields, RN

Denise, in trying to give an explanation for disparities, felt she was unable to offer insight into the phenomenon.

I don't have one. If all the researchers couldn't come up with one, I certainly could not! They say they think it might be environment or socioeconomic, I don't know. You got poor blacks in Detroit, you got poor whites in Hazel Park, you know. So I don't know, there are other counties, other states, that have the same issues and I don't know that they're all poor, and on aid, and that kind of thing. Maybe it's something in our blood that came from Africa. Because we have had judges, and different professionals and as far as we can tell they've got support at home, have supportive families, the FOB [father of the baby] is involved or they're married. Maybe there should be some genetics involved. I mean you would think the rates should be more even, at least with all things being equal, and that is not the case.

Denise made a key supposition in that last sentence. "I mean you would think the rates should be more even, at least with all things being equal, and that is not the case." But, all things are not equal in this country. The impact of this inequality is discussed in the concluding chapter of this work.

What is the Role of the Family?

The role of the family is an important one, and can make a tremendous difference for the pregnant woman. Whether providing emotional support and encouragement, hands on assistance, financial help or simply advice, their role can be vital. How the role of the family is assessed in the terms of their contribution to the risk for preterm birth by providers is clearly a reflection of their interaction and experience with families over the years. Dr. Jones evaluates the impact of the family based on how much the family supports or contradicts her teachings with her patients. Because of this doctor's resolute belief that education is all important, she speaks of how families

can buttress and sustain positive health behaviors, or do the opposite. She provides as an example of drinking during pregnancy.

Carolyn Jones, MD

A lot of things we know and believe come from how we were raised, or the environment around us, so it depends on what environment the family is in, you see. A lot of what we know comes from what our sisters told us, our grandma told us, or our auntie told us. If the family values the education about taking care of yourself while you are pregnant, then the patient tends to follow suit. And you will find that there is a family member that will accompany them to the visits who will piggyback on the things I may say, like “you can do this”, or “you can’t do that.” It will reinforce positive behavior as they believe it, as they agree with the position, or if it’s just caring about the pregnancy they will be present to help with the reinforcing with what the physician says.

Dr. Jones describes the positive support family members can offer that aid in reinforcing her teaching. She also describes how family members can contradict her teachings and subvert her influence.

If you have a family that collectively does not value that education or maybe just is not exposed to that, then what they will do is reinforce the negative behaviors, saying it’s okay for you to do this, it’s okay for you to do that. I have had patients that were interested in the health of their baby that called me and said my aunt said it’s okay for me to drink, it’s her birthday, or it’s only on New Years’ Eve. “Dr. Jones I’m wondering is it okay,” waiting on my co-signature, and I’ll say, , “No, absolutely not, don’t you pick up that glass, in fact you go to the party, you say ‘Hi” and you leave.” So, obviously there’s some belief that it’s okay if somebody else did it, and they don’t care what the doctor says, they just feel like it’s not that big of a deal, and for whatever reason that patient thought to ask me first. . .which was a wonderful thing.

Dr. Jones views the family as having the potential to corrupt her message, and sees that she, herself, must offer support that the family may not. Charlene shares a similar view but recognizes that many women need hands on assistance.

Charlene Davison, CNM

I think that women, when they’re pregnant, they need to be nurtured. And I think they need somebody to prepare some meals for them, they need to have someone fuss over them, they need to have somebody take the responsibility of

the other children. So I think they need that, 'somebody cares about me' and I think in turn they can care about themselves and their unborn child.

Charlene alludes to the ongoing need women have to know that someone cares, even if it is not a family member. Many women do not have this community of support, however, and Denise discusses both the difficulties women encounter when they do not have family support and why that sometimes happens.

Denise Fields, RN

Just being supportive and you know being available. You know, able to help them with the needs they have at home. You know, is there someone who can prepare meals, or make sure you have food? Is there someone who can babysit for your other children? Can they pick them up from school? You know, because a lot of these women don't have, the father of the baby may not be involved, so, you know that makes it a little more difficult too. And you know a lot of these women, especially if it's not their first, you know the family is upset, sometimes, because you're having these kids and you can't really take care of them, you know. So now, in the interim, you're sick. Now you gotta help.

But we do keep women because they don't have the support they need at home to be at rest, and on bedrest. If they're in with preterm labor, I tell everybody to stay in the bed, drink your fluids, you know if they get to go home, you know not to have sex, not to do anything, let your family cook, bring you meals, if you've got a bathroom on the first floor, go downstairs and just stay there all day. You're not going up and down the stairs. Get somebody else to help. We've had women who, and you know it's sad, and we do see it more in the black ones just because they don't have support, but they'll go [home] and they'll be on bedrest, but they gotta walk their kids to and from school every day and that's not bedrest.

As with Denise, Nicole's commentary is more focused on what women experience with a lack of family support, something she has observed frequently on her unit. She directly attributes some of the "bad outcomes" the patients have to this.

Nicole Greene, PCA

Just be here for support and you know I see a lot of the young ones they get that consult, they call their families, they come in they're upset, and you know they want her to leave the hospital, and they don't have that support, most families, cause we get a lot of people from broken homes or they may come from a shelter and just don't have anybody, so some of them need that positive somebody,

somebody to just talk to them. So those I usually go in more often you know, and talk to them and follow up with them because a lot of them don't have family support. Even the moms that get discharged, they don't have a ride, we have to get cab vouchers, they don't even have a ride home. It's like it's no support there and if they have children, and that's another reason our patients can't be here and get the care they need because they have other kids at home and nobody will baby sit for them so they have to sign themselves out to go home and care for the other kids. And sometimes the outcome is bad because they can't be here, be continuously monitored, and you know all those things because they have to go home, because they have nobody for their kids. I see that a lot, a lot of stress.

This description emphasizes the downward cycle that ensues for women who are already living with limited resources—emotional, material and family—and who then end up hospitalized for preterm labor, which further strains the few resources they already have. Mounting stress is a consequence, as Nicole concludes.

What do you wish your patients knew?

The responses from the providers below are a direct response to the question, “What do you wish your patients knew?” This open ended question was asked without added clarification. Particularly interesting is the diversity of responses among this small group. The providers suggested their patients needed to know about making health care choices; the benefit of positive thinking; the use of contraception; that by taking good care of themselves they take care of their unborn babies; the responsibilities and risks of pregnancy; and that they needed to decrease their stress.

Carolyn Jones, MD

I wish they knew that they had a choice in their health care, that they could actively seek out something that they would want for their health care and be able to follow out to the end, particularly in obstetrics. That they did not think that you just see someone for a little while and then just show up wherever, anywhere and somebody is going to deliver your baby. That they would know who's delivering their baby and know the difference between a nurse and a doctor. And that they wouldn't just accept anything. That's very frustrating for me.

Frederick Toma, MD

What is it that I wish they knew? That there is something to be gained from positive thinking, number one. Number two, that we don't understand it, we don't know how to prevent it, we don't know how to treat it very well, so the best we can hope for is that we pick up on signs and symptoms of premature labor early and maybe we can do something about it. Even if it is not stopping it, just giving them steroids in a timely fashion can decrease the potential bad outcomes that stem from prematurity, decrease the incidence of them.

Charlene Davison, CNM

I think that if they just knew, 'If I'm okay, this baby inside of me will be okay.' And then let's try to make sure I'm okay 'cause this baby is depending on me. I am the only one that this kid has. You know, sometimes I might have a mom say she hasn't eaten and this may be three o'clock in the afternoon, and she hasn't eaten since the previous night. And then I go over the whole thing where you wouldn't keep a newborn from eating for 18 hours and that type of thing. And them picking people to have kids with, you know that is important too, you know selecting who you have your children with. Who is going to be supportive of you and really tapping into the supportive resources in your life. I talk to them about their partners but sometimes it's kinda too late, because it's already a done deal, you know, but for the future, look at those kind of people that are going be supportive to you in your life, and support you and this baby.

Denise Fields, RN

I can go back to the beginning: that they don't have to screw every man they go out with, they don't have to have a baby by every man they date, that they meet, now I don't really advocate abortion but it is available, you know. I mean that's how it should be. I think the world probably wouldn't be as it is if more people took responsibility for themselves and their children, and they don't, a lot of people don't.

They need to know about birth control, where to get it for free. Because the health department offers stuff for free. Really if they just made these guys use a condom, you know that would help. Cause I know a lot of women they don't like, they don't want to take the pill because it will put chemicals in their bodies and you know they always have an excuse or reason, or you know I couldn't get to the doctor so I got my first Depo, but now here it is 6 months later and I didn't get another shot, and now I'm pregnant, you know. So, education, education is a big piece as far as how to take care of themselves. I think they, I just think they think it's okay. That's how it's supposed to be. You know, I got 10 kids by 10 different daddies, that's okay. I don't see it as being okay, if you can't take care of them.

Which means, providing what they need, clothes, food, shelter and education, preferably college, and they can't do that.

Nicole Greene, PCA

Well, first of all I wish that when women got pregnant they knew all the responsibilities, you know, that come along with the pregnancy and you come in the hospital and wherever you go and you're not sure, you're always supposed to ask questions. Or have somebody here with you to be your advocate if you don't feel like you will fully understand what's going on. I think that's what it is. . . Cause some of the women that are really, really sick, and try to sign themselves out because they don't understand, and we have some that go home. Like we had one she went home and ended up dying the next day because she was preeclamptic but she was like, "Y'all ain't doing nothing but checking my blood pressure" and then she dies. So, we get a lot of sickle cell moms and they tell them after the first baby don't have another baby because the moms usually die, but we have some that'll come back and they'll have another one, and they die. So it's like nobody's left here to take care of the kids.

Vivica Westmoreland, PCA

A lot of things I think they need to know well but number one, don't stress! Cause when you stress that makes the baby stressed and you don't want no baby's heart rate dropping or nothing like that because the more you stress, the more the baby stresses, so just try to stay relaxed. Like I had to do, you just gotta have to pray, and just think about it and go from day to day. Try to eat healthy and just stay away from stress.

What is the Role of Stress in Preterm Delivery?

The providers were not asked directly about stress, but follow up probes were initiated once they introduced the topic of stress. The discussions that follow emerged spontaneously from the informants or were elicited from probes. Dr. Toma sees stress reduction as a major concern.

Frederick Toma, MD

The thing that patients need to do is to try to decrease stress in their lives. They implied that stress has something to do with prematurity, but when you look at programs of stress reduction they don't seem to help. But, given that's the situation, and I don't have a magic preterm birth pill, I would encourage them to decrease the stress in their lives, to eat well . . . to eat well and decrease the stress in your life BEFORE you get pregnant! Those are two of the main things.

I think that families can increase or decrease the stress level, so yeah having or being in a family situation where the stress is low . . . and another thing, besides decreasing stress and good nutrition but making sure that you are in the best of health before attempting pregnancy, becoming conscious of the attempt at pregnancy as opposed to having pregnancies each time by accident or by failure of birth control making a conscious effort to plan for pregnancy and making sure that the interval between pregnancies is two years or more and that during that two year period of time good nutrition, stress, exercise, good health.

Charlene Davison, CNM

Charlene views stress as a major factor in preterm birth, and gives examples of the type of home situations that create stress in the lives of her patients. Her rationale is that when there are an abundance of life stressors, no special care is taken with the pregnancy, and the pregnancy suffers.

I think that overall it has an adverse effect when a woman is up under a tremendous amount stress in that she has a lot of responsibility with other children, and she is carrying this kid, and she is also pregnant with another child and she doesn't have the support at home she doesn't have someone to go there as a sounding board, she's carrying a lot of responsibility in terms of the home, maybe she's living with her mother and she has these two other kids, and there's no father around and her mom is sick and she's not there for her, and she's trying to maintain, and it's just too much. And I think that this pregnancy is just added responsibility that tends to suffer just like everything.

Nicole Greene, PCA

For Nicole, a major source of stress is the living or home environment of the patients she sees. While she identifies being unmarried as a risk, she also describes how an unstable home life makes it difficult for women to comply with bedrest, and how that further exacerbates their medical condition.

Yeah I might say maybe four out of 50 of the women might have a husband to support them it's really a low number, the people that have support, and they usually have a bunch of little smaller kids at home and the family they may keep them one night, but then they are like, "I'm gone, I can't watch your baby" or yeah, so that's the problem that a lot of them have, they just can't stay because they don't have that support, and a lot of them are young and their parents are young too, so they don't want to be bogged down with no babies. They don't

want to be no grandmother, so that's why a lot of our patients don't do well I think because of that, and they don't have any support they're just out there having babies.

Well a lot of them, the blood pressure thing, we see a lot of that. Then I think a lot of them are so stressed about being here and then a lot of them receive assistance from the state, and if they're here and don't have the paper work in or are not able to go to Work First [a work program required for women receiving public assistance] the they may cut them off while they are here before they can get their paper work turned back in and they're stressed out about that because you know they may not have nowhere to stay when they leave the hospital you know, so they may be homeless, and then one lady was here, they broke in her house and stole all her stuff while she was here so she had to leave.

And one of our patients who delivered preterm, her boyfriend would come once a month and take her bridge card and go spend all her money from her bridge card and she ended up going to a shelter because her mother said she couldn't live with her because she wanted the boyfriend to live there too. She was only 19, so and she ended up delivering early. Then, and a lot babies they stay in the nursery because they don't have like an adequate place for them to live and they usually just end up being in the system and it's sad because I see them now, 18, already with 4 kids. They're already stressed before they get here, not being able to take care of your business, you know your family don't want to be bothered, you know you don't have that family to support you in trouble.

Stress, I think stress is probably number one. There's probably a lot more stress. The average Caucasian or any other race that comes in here usually has a husband, like a good family support group or something and most of the girls that come in, the majority of the patients come in and they just have baby after baby after baby and just they don't know what they're doing, they just having babies, and they know they can't care for them and then it's like everything is our fault, if we don't provide this service, because some like want a car seat, they want to know where they can get a crib. They want every resource to take care of that baby and they ain't thought about none of this before they got pregnant, so then they want to put it on us, and it's our fault because we don't give this, this and this. . that's not how it works, they need to plan!

Nicole concludes this portion of her discussion about stress by relating a story about a patient who was a victim of domestic violence. She said that domestic violence is sometimes the precipitating event that leads to a woman being hospitalized for preterm labor symptoms, and then that woman is left in the fragile situation of not being able to

go back home when she is discharged. Stress is a key factor for her in explaining the disparity in prematurity.

What can be done to prevent preterm birth?

Denise Fields, RN

I don't know, because we see so many that . . . Like for example our premature rupture. We've had patients here in the hospital, that have been here one, two, three weeks and then all of a sudden their water breaks. So we know that they weren't doing anything, that they had good nutrition, that they were getting fluids, that they were on bedrest and it still happens. And like the ones we keep here and then they still go into labor. We've done all we can do, at least all we know to do right now, so, I don't know. If you come up with something, though, let me know, and I'll spread the word (laughs).

I was going to comment about how things really haven't changed that much. This has been ongoing. I have been working high risk for 20 some years, and the only difference, well I'll say the biggest difference is that we can get them further in their pregnancies, and that we are saving babies at younger gestations. So over the years they have been able to do more with the preterm baby once its delivered, so that's good, if they are going to have a quality of life.

Nicole Greene, PCA

Now the ones that aren't ruptured as far as like high blood pressure and all that, you know eat the right things and when they tell you you're on bedrest, stay on bedrest. You know just be compliant to what they tell you do to in the hospital and I think you'll have a better outcome, than to just pretty much figure well this isn't helping so I'll get up and do what I want to do.

Some patients say I don't want to take any more of those pills or, you know, getting their blood drawn to check their levels on different things, a lot of them don't want that done. Or some that are diabetics, gestational, they have family bring them fried chicken, and things they shouldn't be eating and their blood sugars are high but some of them just don't care—they are just going to do what they want to do because they figure if they went somewhere before and they had a baby and they told them to do XYZ and they did just the opposite and it worked for them then they figure it's going to keep working for them so I don't have to listen to them because I know what works for my body.

Carolyn Jones, MD

You know, making sure that you don't add stressors to the pregnancy that can affect the health of the pregnancy. The life habits, lifestyle modification, if there

is any kind of substance abuse, diet, keeping yourself healthy, just coming to your doctor's appointment so that we can catch things in advance. Having the connection with the physician is something they can do, having consistent prenatal care, and understanding the things we are trying to prevent from happening in pregnancy all those things are things they can do to contribute, so just to avoid those bad things from happening. I tell them all the time, if you go to the ER I better not hear about you going to the ER and you don't call me. You better call me because I need to know what it going on with you . . . I am telling them that because it is not the expectation.

As providers discussed their own understanding of the reasons for preterm labor, the question next arose regarding the shared understanding of risk between the care givers and their patients. Overwhelmingly, the providers did not perceive that there was a shared understanding.

Do your Patients Share your Understanding of their Risk for Preterm Birth?

Charlene Davison, CNM

No they do not. I need to tell them about that. When I see that they have a bladder infection then I need to let them know, I want you drinking fluids, I want you taking these antibiotics, I want you to space them properly and I want you to finish the whole thing. And I want you to get the prescription filled, because often times you'll see women, you'll diagnose them with something, you'll prescribe something, and then they don't get the prescription. So a lot of times I'm running out during the day getting prescriptions filled. So the understanding should be that the way we are going to fix this is by taking this medication. But, it just doesn't always connect. You need to take the medication that we gave you in order to get rid of the problem, because it won't get better without it. So, they'll come back to see you, without getting the prescription filled! So I've seen that a lot.

Well I tend to think that they don't always necessarily, see the importance of protecting themselves from sexually transmitted infections. In that they will get an infection, that will get treated, then they will expose themselves again, or they don't insure that their partner has been treated. So they'll come and repeatedly have the same infection, infection, infection, and that's a problem. I tend to also think they don't necessarily look at nutrition because you'll see a lot of the group that I deal with eating the ramen noodles or they're eating potato chips, or they're drinking pop and nutritionally we need to build them up. You know, just to put themselves in an optimal position with this kid, and do what that they do need to do.

Denise Fields, RN

No. Many of them don't. You know I'm coming from a medical perspective, and all they say is, "I had John at 28 weeks and he's fine, so I'm 28 week now, so it's okay if I have this baby". So then I have to tell them that you need to go to 40 weeks. The further along you go, the better. And just because John was okay doesn't mean that this baby is going to be okay. We're keeping you to try to prolong the pregnancy and everything I tell you to do or not to do is based on that.

A lot of times, once they come to the hospital, regardless of what the reason is, they're ready to deliver. It doesn't matter how many weeks they come in, they think they can have their baby now, they're ready. So it doesn't matter, 22 weeks we hear women say that. "No sweetie, you can't have your baby this early, even if you're now at 36 weeks." And now the big push is 39 weeks, so a lot women don't understand that. "Well they induced me at 36 weeks with my last one." But God made it 40 weeks for a reason.

I think that's usually the biggest misunderstanding. Either they have had a previous preterm baby or someone they know had a preterm baby, and the baby was fine. Now if they had a baby that's sick, then they make look at it a little differently.

Nicole Greene, PCA

I think some of them, some of the older ones, but some of the young ones I don't think they really understand. I think the younger ones are pretty much, "well whatever you tell me because I really don't know nothing anyway, so okay" they pretty much buy whatever you tell them. The older ones, they'll ask questions. I see a lot too that the younger ones they always want to do an amniocentesis on them, and like they wanted to do an amnio on me and I'm like I'm already ruptured, I mean you know I'm 27 weeks, why do you need an amnio, you know the lungs aren't mature, so NO! But a lot of them agree and I think we had one last week she was 19 weeks she agreed to an amnio and she ruptured so then she came back, she ended up losing her baby. So it's just like you know they come in and they talk to them and they get them to agree to a lot of things that they really don't understand, but they'll go ahead and do them anyway . . . thinking that because you are a care provider you're telling me what's best, so they don't ask questions, they just do it.

Nicole raises the concern regarding the dominant role of the physicians and other care providers, and the subordinate position of her patients in the hospital. In light of their

pronounced vulnerability, she suggests one misunderstanding patients have is that they must accede to their doctor's requests.

Carolyn Jones, MD

Dr. Jones highlights key divergences in how she perceives risk for her patients, and in how they understand risk. One concern, raised in earlier passages, is the belief by some women that if the outcome of her previous pregnancy was acceptable, despite the mother's unhealthy behaviors, then there is no need to make lifestyle changes in the current pregnancy. This same mindset, of using the perception of previous pregnancy experiences to guide present behavior, contributes, according to Dr. Jones, to a lack of understanding of the substantial risks to infant born preterm.

And they say well everybody else was fine, because anytime everybody else from their perception looks fine, even if they're not, the babies look fine, then you can do it. Marijuana is frequently used on a regular basis in pregnancy and this goes to something else about that socialization or acculturation . . . I'll ask a patient "do you smoke?", and they'll say "yes", I'll have to be careful because I don't know which "smoke" they are talking about. The language now, do you smoke, means marijuana, and I used to ask, well how many cigarettes do you smoke and they'll say, "Oh, no, Dr. Jones, I would NEVER smoke cigarettes, I smoke some weed, but I would NEVER smoke cigarettes!!" So they smoke marijuana on a regular basis, and that's not perceived as being so bad as smoking tobacco, with society now, with people doing it on a regular basis.

And I have to find a way to prove to them that smoking marijuana in pregnancy is just as harmful, if not more harmful, than smoking cigarettes. If they've had what they perceive is a good outcome, despite their bad habits, then that's going to be a road block to me getting them to understand that it's not healthy for them or their baby. However, if I am successful in educating them about the different outcomes, whether I have to do it in a pictorial sense or in a verbal way, where I talk it out in words, if I can accomplish that then I can get some change in the behavior and I can show them a different outcome . . . So, sometimes the perception is the same and sometimes it's different. It just depends on the individual.

And if they've had a premature baby, they'll say yes Dr. Jones, but that's just how it is. Well no, that's not how it's supposed to go. One of the things that's frustrating to me is there is a population out here that is learning disabled,

socially and academically. Those are probably the most challenging, because, no matter how much you try to explain it, you are never really sure if they're grasping what you're saying. So in that sense the physician has to spend more time with them. And sometimes as physicians we don't feel we have that time, but some kind of way we have to commit something to helping that patient understand what it means. More visits, more pampering . . . they can't read, they don't read, or what they read they don't understand.

A lot of them they say, well it happened before so it's going to happen all the time, and then they just accept it. And we shouldn't be in that situation. Understand that we can be empowered and be able to be in control so that we have a different outcome next time. But if you accept it, then you accept that outcome every time and you perpetuate the problems that follow.

Dr. Jones problematized the preconceived notions on the part of patients as to what they regarded as acceptable behavior during pregnancy, and she found problematic the normalizing of preterm birth among women who had delivered premature babies in the past. A dominant theme was the problem with a lack of education, with all of its nuanced and culturally informed meanings. The issue of education as a focus of the differences between patient and provider is also addressed as a serious issue for Charlene. She describes a consternating “disconnect” that obstructs her ability to impact behaviors through teaching.

Charlene Davison, CNM

I think certainly education is very important, and it's very important that they respect and trust the person that's educating them as well. There is certainly a disconnect. They do not connect, they don't see anything wrong with their diet. They see nothing wrong with eating potato chips, this is for breakfast, they'll eat potato chips, pop, they stop at the local gas station, and they fill up all this stuff in their bag, and they'll come to you with this stuff, and you hardly ever see them with water, so you're educating them in terms of the dehydration, and not getting dehydrated.

But I can't encourage them like, to breast feed, you know, that type of thing. They're just not going to do it. And then you get them coming to you, half way after they've had their WIC, and they need some emergency milk. And you can tell them from the beginning that this [breast feeding] is an economical way to feed your baby, and it's a healthy way to feed your baby, and this is the gold

standard for feeding your baby. And you are going to run out, and I get kids who come to me all the time for emergency milk and I just don't have it because a lot of these services are drying up, so but they just don't see it that way, and they want to give the bottle, it's almost as if "I'm not good enough" you know, I can't possibly be good enough to feed this baby.

Charlene adds a new dimension to the problem of nutrition, and the reluctance of mothers to breast feed, when she perceives that there is an aspect of lowered self esteem among these young women that makes them feel, "I'm not good enough."

In this next section, Dr. Jones refers to her patients and their alternate, culturally constructed ways of thinking, she disqualifies their knowledge. The situations she describe illuminate her construction of the dominate-subordinate physician-patient relationship.

Carolyn Jones, MD

There is what I call a social retardation where socially, in the main stream, that person may think very different socially than what you are used to. So academically they may be fine, cognitively they may be fine, but from a social standpoint whatever cultural environment they are in, whatever rules, regulations and standards that have been set in their population and reality, it may not fall within the norm. Then it appears that what you would consider normal, they don't perceive it as normal, or what you would perceive as strange is very normal to them, and somehow you have to change their reality to see that well, I know that is how you experience things socially, but really this is how it is, and this is what we need to cover. I'm trying to think of an example.

Okay, this isn't necessarily related to obstetrics. There's a belief that because the male partner in a relationship has not expressed symptoms of a sexually transmitted disease, that you did not contract that disease from him. You contracted it from his other mate, so therefore it is the other mate's fault that you contracted the disease, and he is therefore exempt from responsibility. That helps them maintain the relationship with him because now there is an excuse, and that puts all the responsibility on the other person. So some of that is education, but I don't expect the entire population to understand, but at the same time there is a mainstream population that understands that if you had intercourse with that guy that he's the one that contracted it to you, and you didn't really need a science book to explain that to you.

Dr. Jones then returns to her concern with the prenatal care system, and the difficulties her patients encounter in negotiating it.

They get assigned to whomever, they don't know where to go, who to go to, they don't have any say in who their doctor is with that Medicaid card, that HMO and I tell them you already have a doctor, that's me, but they call themselves following instructions and she winds up in another doctor's office, and she was getting care from both of us, and I said, you have to choose. I had a patient who had the same blood test on the same day. We had already started prenatal care, so why would you go back over there? But it was like she just didn't get it. She said they told her to come back, so she did. She just showed up they drew the blood. So I get a call from the lab, we've got two specimens, they're the same exact thing. She didn't know! How do you not know, how do you not know? That goes back to that term I used, social retardation. It doesn't make sense. But they're trying to do the right thing, but they are just doing as they are told. But they're confused because of how the system is set up.

What is a Good Outcome?

The question of what would be considered a good outcome was designed to elicit the expectations and goals of the providers for women at risk for preterm delivery. Charlene was worried that her teens would not be compliant with attending the high risk clinic if they developed complications. Her good outcome was reaching a mature gestation without incident.

Charlene Davison, CNM

I would consider a good outcome would be if we could get her to at least 35 weeks. And then I would feel like mission has been accomplished. And I think the fact that I am at the school four days a week, then the students tend to have access to a health care person they can come to and they can share things with. And I think that helps. So I would not want to turn them over to a high risk clinic, because a lot times they just don't go, they just will not go.

Patients cannot reap the benefits of specialized care if they do not attend their prenatal appointments so compliance with health care appointments took priority over the possible need for her patients to see a high risk doctor. There is also an indication from Charlene's discussions that care and support may yield more a significant improvement

in outcome than high tech surveillance. For Nicole, 28 weeks gestation is a reasonable goal, perhaps in part because infants born at that gestation have been doing fairly well, and perhaps in part because that was the gestational age of her preterm infant.

Nicole Greene, PCA

If she can get to about 28 weeks and you know a pretty healthy person, drug free, their babies usually do pretty well, you know they bring their babies back to see us and most of them do pretty well. You know we have few that don't, but most of them do, for the most part. And we have a lot of multiples also they go preterm, and they usually do pretty good, too, but most of our multiples are usually Caucasian women.

African American women are far more likely to spontaneously conceive twins, or multiples, but there has been a large increase recently in multiples born to white women as a result of assisted reproductive technologies (ART). In fact, part of the reason there has been some narrowing of the disparity in premature birth between blacks and whites in the metropolitan Detroit area is because the preterm rate due to multiples has gone up among whites. When Dr. Toma speaks of a good outcome he shares a very pertinent concept when he tells of his pact with his patients. He is encouraging a positive outlook and strengthening their resolve. His patients would be amused to see him, a man who is over 6' 6" tall, dance a little jig.

Frederick Toma, MD

My first thought is that you are getting a biased perspective because I am a high risk obstetrician and have always dealt with some of the highest risk pregnant women around so for me a good outcome is a delivery after 32 weeks. In fact, unfortunately, I have developed the 32 week dance, and I tell my patients that if you make to 32 weeks I will come in and do the 32 week dance for you! And actually I was put to the test some two weeks ago, one of the privates called me and said that one of his patients was in for a C-section at 38 weeks and she said I that had promised that I would do 32 week dance so I went over and did it right in the pre-op area. Beyond that I would like to see a 34, 36, 38 week delivery, but if I can just get her to 32 weeks . . . I know that the risk of major negative premature events drops dramatically after 32 weeks.

What stands out in this statement is that Dr. Toma reflects a belief that offering his patients an incentive might yield a positive outcome. What he is saying to them, in effect, is that they have the ability to affect the timing of their deliveries. At 32 weeks gestation the risk of major morbidities drops considerably so he is exhorting his patients to do their best not to deliver before then. His 32 week celebration has multiple meanings, acknowledging not only the well being of the child, but “success” of the mother as well. The understanding between the physician and the patient, when this occurs, is that this was not luck, but the result of agency. Dr. Jones offers a differing view of what she would consider a good outcome. While most of the providers offered a gestational age range, Dr. Jones focused on the doctor-patient relationship.

Carolyn Jones, MD

A good outcome for her would be her perception of having a consistent relationship with a physician. Her perception is different. Often times, they will ask me are you going to be the one to deliver my baby? There’s a disconnection there, and I have been trying to bridge that gap in their minds that it is possible for you to have physician that follows you from beginning to end and through postpartum and then continues your medical care after that. There’s a disconnection between the prenatal care, and the hospital care.

*And that is something that is accepted to the point that even though I said, I am your physician they still don’t understand that that means I follow you to hospital. They don’t get it. I don’t care how many times I say it. Many times they will say, “Thank you for coming to visit me Dr. Jones.” I am thinking, I am not visiting, I **had** to come here today. And they are just so excited that someone has come, that, oh, you care so much, I am like, this is my job. They don’t get it. So one thing, the one good outcome would be her perception of her care is different now. She can compare that to something and now she can make a choice of what kind of care she wants to have when she becomes pregnant again. She sees that in caring for her body, there is actually a doctor-patient relationship.*

She will also understand that there are factors that she can control to some extent that help her get a good outcome, and every outcome does not have to be a disaster at the end of the day. She doesn’t have to be depressed about her

pregnancy. She actually, hopefully, will have a full term baby, and know that it is possible, and that every pregnancy does not have to be the same.

Discussion

The providers interviewed shared their candid and detailed observations regarding the high risk women they cared for, and their appraisals of the significant contributors to preterm birth in the black-white disparity. They discussed their dilemmas and constraints as practitioners and their explanatory accounts of where risk was situated.

Clearly, throughout their discourses, the providers envisioned a role for the pregnant woman in preventing preterm birth. By interrogating their beliefs related to the role of the patient, their concepts of causality emerged and were illuminated. The obstetrician, the perinatologist, and the certified nurse midwife primarily constructed risk on three planes: societal/cultural factors such as racism, that lead to poor access to health care, inadequate education and the related lack of good jobs; pre-existing medical factors such as poor nutrition, a late start for prenatal care and a history of preterm birth; and behaviors such as inadequate spacing between pregnancies, substance abuse or not following healthy pregnancy regimes.

The nurse and medical assistants, however, stated that they did not see any striking characteristics of women at risk for preterm labor. They constructed risk based on the behavior of the mother. However, it was evident in their expositions they listed not only objective risk factors, but they described certain types of women whom they evaluated as being more prone to deliver preterm. Stress and stressful situations were often mentioned.

All health care providers expressed some frustration with the limits of modern medicine and their expertise. Some patients, for instance, did not recognize the health challenges of preterm birth to their unborn infants, because they knew of preterm babies who had no apparent complications. Many low income patients had so many challenges in their lives in terms of other children, jobs and lack of family support, that dealing with the extra responsibilities of a high risk pregnancy was more than they could handle. Providers complained of other patients who displayed attitudes that seemed to indicate a complete disregard for the health of their babies.

One concept expressed by the providers was that the mother's commitment and determination had an impact on the outcome of the pregnancy. Dr. Toma's offer to do a dance if his patients made it to 32 weeks, and Nicole's observation that if patients "really wanted" their pregnancies (although she did note exceptions) they would do better, are examples of this belief. They implied an intangible that went beyond simply adhering to medically advised regimens. Dr. Toma also stated "I don't have a magic preterm birth pill," conceding that he did not have all of the answers. This was in contrast to the general concept that, "Doctors are trained to present a face of decisiveness to patients, even when they are only certain about their uncertainty" (Handwerker 1994:669).

The term "social retardation," which may sound harsh, was used by Dr. Jones in reference to a population that, in her estimation, was not be able to fully comprehend or adequately integrate the multiple aspects of their care and their own advocacy roles in successfully negotiating a complex system. Agency was lacking and patients did not demonstrate a comprehension of the broad view of their health care. Trying to counter

the view of patients that having preterm babies is normal was a source of great concern for all providers.

In spite of these frustrations, most providers developed strategies to communicate their knowledge to their patients, with a goal of providing the best outcome for the current and future pregnancies. These strategies ranged from Dr. Jones' interacting with a patient long enough to "get an idea of what it's like to live as them", and individually designing treatment and the way treatment is approached, to more standardized lists of questions with associated medical interventions.

When providers discussed cases in detail, most referred to low income women, only occasionally discussing the fact that for African American women of all socioeconomic levels, disparities still prevail. The providers had multiple explanations for this, as does the medical research community. One informant mentioned that even though an African American woman may have a comfortable marriage and middle class life style, she still experiences the stress of others in her family and community who are not so fortunate.

When Dr. Toma suggested "good old fashioned racism" he ventured into a direct discussion with a term not employed by the other informants. He, however, also attributed some aspects of disparities on the breakdown of the African American family and a lack of responsibility.

The health care providers constructed risk from a variety of social, economic, health, psychological and personal factors. In assigning responsibility, many started with socioeconomic factors that caused women with limited resources and support to

fall into a downward spiral. Regardless of the socioeconomic status, however, the risk was most often situated at the level of the individual woman.

CHAPTER 11

DISCUSSION

“African American women, whose rates of preterm delivery and infant mortality are the highest in the United States, have unique experiences of stress, yet there is a dearth of studies on African American cultural factors pertaining to stress, emotion, or pregnancy” [Behrman and Butler 2007]

This anthropological investigation, in recognition of the large and very urgent epidemiologic concern to reduce preterm birth, was constructed to add a dimension to the understanding of how risk for preterm birth is conceptualized by women, their families, and health care providers. The importance of such an investigation is that it provides the opportunity to understand the experience from the perspective of those facing preterm delivery, making insights accessible that were not previously available.

By utilizing case studies of African American women hospitalized for pregnancy complications, and enhancing these case studies with the voices of their families and health care providers, a new dimension of focus has been added to this complex issue. The emic perspective on risk that is provided by these voices is an important perspective that is often missing, or understudied, in the analyses of preterm labor. Taking this perspective into consideration could ultimately lead to a reduction in the risk for African American families, by contributing to the development and delivery of better adapted and better informed services.

Unpacking the concepts of risk held by the various actors in this research, and demonstrating the ways in which these models inform behavior, provides for a better appreciation of the concerns, values, and practices of the informants. It also helps to identify areas of disagreement, misunderstanding and conflict among different

conceptualizations of risk, and illustrates what it means to be both at risk and to be a source of risk.

Several studies have endeavored to understand how risk for preterm birth is conceptualized by pregnant women (Mackinnon and McIntyre 2006; Ray 2006; Possamai-Inesedy 2006; Gupton et al. 2000; Heaman et al. 2004; Williams and Mackey 1999; Handwerker 1994), but none have specifically compared and contrasted the differently located perceptions of pregnant African American women, their families and African American health care providers. The very high and disproportionate rate of preterm birth among African American women in the United States has often led to these women being labeled *high risk* in epidemiological studies. However, how that risk is perceived, explained, and located, within the context of their lives, has not been studied.

Risk, and perceptions of risk, are culturally constructed. The language of risk emerges in many forms, shaped by the culturally informed perspectives of individual people, professional disciplines, and the fields within those disciplines. Risk touches every aspect of health and human welfare, but the dimensions of risk, as conceptualized in various fields, are qualitatively different (Jacobs 2000). Kaufert and O'Neil (1993), in their writing on risk in childbirth, discuss three languages of risk: clinical, epidemiological and lay. Yet, within each of these categories, the various actors, such as physicians, nurses, patients and family members, construct risk differently. In this study, a theoretical framework that positions risk assessment within the structure of society provides the opportunity to analyze the findings of the study in a manner comprehensive enough to include the multiple variations in how risk is

perceived. The value of this approach is in the interrogation of social norms concerning motherhood, pregnancy and preterm birth among African Americans, and in the revelation of how these norms impact the evaluation of risk. This interrogation also advances the role of medical anthropology in pregnancy related research.

Historically, research in anthropology on pregnancy and childbirth has focused through a feminist lens, pushing back against the patriarchal and technocratic intrusion into processes that are viewed as natural, and uniquely female. The medicalization of childbirth is a primary concern. Robbie Davis-Floyd, in her book *Birth as an American Rite of Passage* (2003) compared the technocratic versus the holistic belief systems about childbirth, and how the biomedical orchestration of childbirth is at odds with the normal physiological processes of both the mother and the baby. When risk has been discussed related to reproduction and childbirth in anthropology, it often addresses the dominance of western technology and politics in the birthing process, and the resultant risk of untoward consequences for the mother or infant at the time of delivery (Reiger and Dempsey 2006; Possamai-Inesedy 2006; Davis-Floyd 2003; Martin 2001; Ginsburg and Rapp 1991; Jordan 1993).

In other disciplines, such as nursing, studies on risk in pregnancy have often focused on comparisons of how much risk is assessed by the patient in relationship to how much risk is assessed by the health care provider (Heaman et al. 2004; Gupton et al. 2006; Gupton et al. 2001; Heyman 1998; Heaman et al. 1992). This study, however, did not seek to compare the relative assessments of the *level of risk* by the various actors, but rather where these actors situated the *source or location* of the risk. Was the

risk under the control of the mother, the physician, fate, the setting in which the mother lived, or some biomedical factor such as genetics?

Anthropology seeks to understand the illness experience, and how it is explained in the context of perceptions of vulnerability and responsibility. Understanding where these actors identified the locations of the risk, and the way they prioritized needs, offered cues as to why certain behaviors were adopted or avoided, and where sources of healing may be identified.

“It Ain’t About You Anymore, It’s About the Baby”

Case Study 1 demonstrated how maternal behaviors were implicated as the cause of preterm birth, and was the explanatory model with the highest degree of convergence among the women, their families and the providers. In concert with the medical model, all shared the belief that the ability to control the outcome of the pregnancy resided heavily within the individual woman. While offering varying rationales and perspectives regarding this assumption, each respondent’s answers resonated a version of this theme. This particular attitude was similar to the findings from the Shivgarh Block, India (Darmstadt et al. 2008), where women were judged to have committed certain types of bad acts if their infants were born unhealthy. Although the culture was different, the attribution was the same. For example in the case studies and the provider discussions, the respondents asserted that pregnancies spaced too close was a factor in repeated preterm births:

- “ . . . well what I coulda did was keep my legs closed, really and truly and waited until my body healed, but I didn’t.” *Precious Perry*

- *“yeah I had kids back to back, yeah I been pregnant and I probably shouldn’t be.” Stephanie Walker*
- *“I spoke to her...you had two pregnancies in a row...what kind of toll do you think that takes on your body?” Sherry Carter (Stephanie’s Mother)*
- *“...a lot of times these kids are born so close together...she hasn’t given her body a chance to recuperate...it wears on you...and tends to show itself in signs and symptoms of preterm labor.” Denise Fields, RN*
- *“the majority of the patients come in and they just have baby after baby after baby and just they don’t know what they’re doing, they just having babies.” Nicole Greene, PCA*

The comments by Nicole, above, exemplify an added layer of stigma to the manner in which women at risk for preterm birth have been conceptualized. Risk is not a neutral category, and it includes a connotation of moral behavior and the stigma of immoral behavior. The mother may be seen as immoral because she is putting her fetus at risk. An example of this stigmatizing, and marginalizing of these women, which is also reflective of the pollution concept discussed Mary Douglas, was found in the article by Mackinnon and McIntyre (2006). They interviewed a hospitalized woman who had recently delivered a preterm baby. She commented that she had done everything “right”, and never even took an aspirin. “She described the ‘other women’ who had delivered prematurely as the ‘kind of people they expect to be here.’ These ‘other women’ included a prostitute who took drugs during her pregnancy and a young woman who did not eat ‘properly’ because she was ‘underprivileged’. The women [in the Mackinnon and McIntyre study] gave numerous examples of messages linking preterm

labor to poor lifestyle or behavior” (Mackinnon and McIntyre 2006:66). These were moral judgments.

Morals and morality can be defined *descriptively* as a code of conduct determined by our society (Morality 2002). Right and wrong behavior is specified, taught or implied for a variety of situations, and serves as a marker for full adult status. Theoretically, adults who cannot exercise self-control, especially in such an important area as the health of their children, lose their status or personhood. Sociologists Renee Fox and David Willis offer the suggestion that personhood, “starts with our acknowledgment of the obligations we have to others, and our binding commitment to them through time. It entails taking responsibility for our own actions and being accountable for them, especially for how they affect others” (Fox and Willis 1983:132). Popular definitions of proper behavior for expectant mothers in the United States include the expectation that they will make an optimal birth outcome their number one priority. But, this idea must be balanced with the mother’s personal code of conduct/morality, in which many other factors must be taken into account.

Moral judgments abound in health care, and part of what is considered moral is the ability to control one’s behavior. If the mothers are being judged as unable or unwilling to control their behavior, then they are seen as immoral by those ascribing to this model. As part of western culture, self control is a key value in post-modern Christian morality, and a lack of self control is a violation of basic moral rules. In my research, a “blame the victim” (Lupton 1999a:49) approach was most certainly a nuanced, and at times a compassionate stance, but nonetheless exemplified the dominance of the neo-liberal ideology that promotes individual responsibility, and the

social construction of risk described by Douglas. The concept endured that these women, known to be at risk for a preterm delivery, could, through some form of agency, impact the outcome of their pregnancies. Stephanie's mother, Sherry Carter demonstrated this belief when she stated the following:

I spoke to her about that, you had two pregnancies in a row, both of them are twins and to me she's risking herself. I spoke to her, for her to think about it, on not getting pregnant again and taking your body through that.

One of the major contributions of this study is a detailed view of a phenomenon that is recognized, (Mackinnon and McIntyre 2006; Mackey and Boyle 2000; Williams and Mackey 1999; Handwerker 1994) but not explored in depth—the fact that women had identities that extended beyond, and were far richer than their medical problems. The disjuncture that occurred between the care providers and the patients was in how this was recognized. While attempting to conform to societal definitions of their roles as women, the pregnant participants were often at odds with medical advice. Whether the women felt the need to keep their homes clean, take care of and protect their children, handle the financial needs of the household, or be active sexual partners, they were generally going against their doctors' instructions.

In the three in-depth case studies of the pregnant women and their families, the pregnant women constructed a moral framework that positioned in the foreground their responsibilities to their other children and their homes. They were caught in competing moral frameworks between the individual responsibility to prevent delivering a preterm baby on one hand, and to focus their attention to their home and family on the other. Many times, the woman was faced with a moral dilemma by trying to be in accord with

the behavior and values of a “good” pregnant mother and also as a “good” mom and wife to her existing family. Precious described her problem in this manner,

I feel safe as far as pregnancy issues in the hospital, but I would feel safer at home cause I could know what's going on in my household. Is my house clean you know who's at my house, you know. Who's around my children?

Precious was struggling with this conflict between her role as the patient and her role as a mother. Lupton (1999a:87) describes Michel Foucault's theory of the emergence of governmentality as “populations are ...surveyed...compared against norms, trained to conform with these norms and rendered productive.” Norms such as “good mother,” “good housekeeper,” and “supportive family member” are also strongly culturally reinforced.

Yet, while trying to fulfill these cultural expectations, and do the right thing, the women in this study were not always viewed as moral actors by the providers. Consideration of the moral hierarchies of these women was sometimes lacking. What was left unnoticed was how the women viewed the expectations of their culture, and the greater society, and their ability to fulfill those expectations in their current state. Denise Fields, the nurse on the high risk unit stated:

If they're in with preterm labor, I tell everybody to stay in the bed, drink your fluids, you know if they get to go home, you know not to have sex, not to do anything, let your family cook, bring you meals, if you've got a bathroom on the first floor, go downstairs and just stay there all day. You're not going up and down the stairs. Get somebody else to help.

The instructions Denise gives seem straightforward, but are focused entirely on extending the length of the pregnancy without regard for the challenges a woman would face in fulfilling such a prescription. Bedrest is frequently prescribed for women at high risk for preterm birth, but there are several concerns that this prescription raised. First,

“evidence is lacking that antepartum bedrest effectively prevents premature birth and improves fetal outcomes, yet physician prescribed bedrest continues to be a standard treatment for PTL and other complications” (Williams and Mackey 1999:38).

Malone et al. (1993) demonstrated that by lessening the severity of restrictions from complete bedrest to partial bedrest, not only were the side effects from confinement lessened, but there was improved maternal outcome without adverse effects on the fetus. It can be argued that part of the reason controlled trials have consistently failed to show bedrest to be effective, is because of the emotional stress women experience from this confinement. The physiological responses to stress that are associated with the onset of preterm labor may counteract any benefit that could be achieved through restricted activity.

But, bedrest serves another purpose for the pregnant woman. Bedrest can be a behavioral demonstration of the moral constriction to control herself. Hence, it demonstrates moral personhood and satisfies the health care provider and the family that she is actually a “good” pregnant woman through her symbolic behavior. Maintaining bedrest shows that she can control herself, something the pregnancy suggests she cannot do. This compliance with bedrest, however, presents serious challenges. In opposition to biomedical discourses on risk is the fact that hospitalization, itself, could also pose a risk. As Mackinnon and McIntyre demonstrated, while women who came to the triage unit at the institution where their study was conducted were extensively interrogated regarding their personal risk factors associated with preterm birth, very little contextual information was found in the medical record to address or assess the social responsibilities of the women. It seemed that this kept the focus on

pregnancy risk, “rendering invisible the woman’s life, work, and social circumstances” (Mackinnon and McIntyre 2006:67). There was no indication that the staff had a clear understanding that hospitalization could be risky for the mother and her family. Their construction of risk “did not reflect the women’s concerns about the risks that hospitalization and medical treatment posed to their family members, particularly their other children” (Mackinnon and McIntyre 2006:68).

This finding was also true in my research, where I found, as stated earlier, that the providers, in general, did not readily acknowledge the competing and differently prioritized responsibilities of their patients that may have made hospitalization risky. This discussion of the resources, and the situations at home, surrounds the issue of support. Many women at risk for preterm delivery do not have the type of support (material and emotional) they would need in order to feel comfortable relinquishing the normal responsibilities of their lives, and placing the fetus, alone, as a top priority. The cultural imperative many African American women feel to be able to do all things, sometimes referenced earlier as the “Sojourner Syndrome” (Mullings and Wali 2001), was an additional factor in the difficulties the pregnant women experienced in trying to restrict their activities. Stephanie shared honestly how she worried about both her home and her children. Nicole echoed the concern mothers had, that kept them from remaining hospitalized.

- *“You know, I think about just chilling out, not doing nothing, just letting the house be dirty, I couldn’t do it!” Stephanie Walker*
- *“It’s like no support there and if they have children...and nobody will babysit...they have to sign themselves out to go home and care for the other kids.” Nicole Greene PCA*

- “ . . .everybody don't have the proper support system behind them, and me and my three girls, they all I got.” *Stephanie Walker*

While a lack of support was not expressly implicated as a cause of preterm labor or preterm birth, support was frequently a concern for these women at risk. The lives they had outside the hospital were not manageable without this support, and health care providers erred when assuming there would be others helping or performing these responsibilities for them. In one study, the authors suggested, “chaotic life situations should offer a warning of elevated risk” (Mackey and Boyle 2000:262), and recommended that culturally competent health care workers need to elicit how their clients view health and illness, and understand their condition. Charlene’s solution was similar to what one of the other fathers who was interviewed for this study discussed in terms of what African American mothers, in particular, need.

- *I think that women, when they're pregnant, they need to be nurtured. And I think they need somebody to prepare some meals for them, they need to have someone fuss over them, they need to have somebody take the responsibility of the other children. Charlene Davison CNM*
- *I believe that it's a lot stress from situations for the African American woman . . . maybe he [the husband] could have dinner done when she come home, have a comfortable setting, have her bath water, massage her feet. . . I believe the European woman is more comfortable with her spouse cause in situations that I know of, he might prepare a setting for her before she gets off work, while she still can work, or he might come home and still assist her and keep her at a comfortable zone or point of comfortability where she don't really have to do anything, you know he'll say “kick your feet up baby, relax, I got you. Robert McClain*

Even though a lack of support has generally not been viewed as a precursor to preterm labor, good support systems can be a major asset for women at risk. Although there is a large body of literature on support in the health care field, this anthropological approach was well-suited to examine the topic holistically, and to consider intragroup

variation in the women's experiences. It offers a view of the individual's experience, how that experience fits within the larger social structures, and complements other discipline's literature on support.

My plate is full!"

In *Case Study 2* the main explanatory model identified was stress. Exploration into this model also revealed the barriers and contradictions of hierarchies of responsibility that precluded the women from placing attention to their current pregnancies as their number one concern. "Stress" was repeatedly named as a factor in preterm birth, not only in this study, but in previous research with pregnant women on this subject. All of the women interviewed in the study by Mackey and Boyle identified stress as a major factor in their preterm labor symptoms, and stress was often defined as "overdoing it" (Mackey and Boyle 2000:257). The authors discussed, at length, the conflict these women encountered over their cultural roles as women, wives, mothers and homemakers, and how these women demonstrated their love and support for their families through these roles. Not being able to fulfill these cultural and societal expectations for these traditional roles was stressful and led to tension among family members.

Wadhwa et al. define stress as, "a 'person-environmental interaction' in which there is a perceived discrepancy between environmental demands and the individual's biological, psychological or social resources" (2001:119-120). Although "stress" is characterized in a number of ways, it commonly describes the tensions that arise when people feel they do not have the means to successfully handle the challenges in their lives.

The women who were interviewed in this study used the word, “stress” in ways that could be variously interpreted and that encompassed anxiety, generalized stressors from major or minor life events and pregnancy specific stress (Lobel et al. 2000:546). Their local meanings and folk categories for stress were not specifically interrogated, but the transcripts revealed how these meanings differed. They described stress related to concerns about their unborn infants; stress related to concerns about previous pregnancies with less than ideal outcomes; stress regarding their own health and the ways it impacted their ability to care for themselves, their other children and their homes; and stress about dangerous circumstances in their neighborhoods. Stress, for these women, encompassed labor or work that was physically taxing, worry or anxiety over pressing social situations, tension in personal relationships and carrying an overwhelming load of responsibility.

“My plate is full,” Precious exclaimed more than once, as she details a day revolving around the care of her four children, husband, home, sister and nephew. In the study presented earlier by Williams and Mackey, they found that with their interviews, “participants substantiated the inferior and unrecognized status of women’s domestic and child care responsibilities” (1999:36). And, for Precious, this overwhelming weight of responsibility was a folk category for the way in which she conceptualized stress. This folk category of stress, shared by Precious, was described by Dressler and Bindon (2000) in the discussion of cultural consonance, and how health status is impacted when individuals are unable to meet social and economic expectations. The stress these women experienced, that referenced their inability to

adequately fulfill social roles, also had the potential biophysical impact of precipitating preterm labor and delivery.

Precious also experienced stress, as she described it, from trying both be a patient, and a mother. Generally, hospitalization confers “patient” status on an individual and, to a limited extent, can relieve that person of obligations to certain other responsibilities. This new “patient” role can create a space where moral personhood is not challenged. However, this was not true for Precious, and she felt marginalized as a result of her precarious social situation. While modern medicine focuses on the management of statistically derived risk, more needs to be addressed in terms of the marginal state of persons with that status. Scott, et al. states, “the status of ‘being at risk’ can position the patient or client . . . in a liminal world betwixt health and illness” (Scott et al. 2005: 1877). None of the women interviewed for my study were able to continue their outside employment, and that posed an economic hardship for most of their families. They complained of feeling stress because they were unable to be home to take care of their households, and were unable to manage their finances as well as they would have liked. Yet they also felt stress related to the work of trying to prolong the pregnancy and avoid preterm delivery. Biomedical risk discourses implicate both the woman and her family as having culpability for negative outcomes. In addition, they often are not empowering and do not offer recognition to women that allows them to become the agents of their own well being.

The manner in which the term was applied by Dr. Toma provides another category for stress. He said, “the thing that patients need to do is to try to decrease stress in their lives.” When Dr. Toma suggested this, he was no doubt referring to those

things over which the women had control. The women could, for example, extricate themselves from toxic relationships, but probably had far less control over their ability to remove themselves from toxic neighborhoods and unhealthy work environments. As will be discussed later, there were often structures in place in the lives of the women that contributed to their experience with stress, but these were not structures that they had the opportunity to change.

Precious also described stress as the result of conflict and arguments that arose in her relationships and how this was not only stressful, but potentially deadly.

The stress just does it, cause when I start stressing I start contracting . . . you know when I'm stressed out yelling or going off or you know tryna get my point across to people or in my household or whatever its just terrible you know. It is stressful, it stresses the mess out of baby, and they don't know, stress will kill you! And as it kills you it will kill your baby. I mean I hate to say it like that, but it's true.

While stress was seen as profoundly contributing to the onset of preterm labor by Precious and by many other informants, not everyone was able to identify a cause for preterm birth.

“I would like to know why do I go through this all the time?”

There have been many investigations into the reasons that African American women, across all socioeconomic and health categories, have such high rates of preterm delivery. The many factors that lead to preterm births and impact these statistics are recognized, but don't adequately account for the disparate rate of prematurity. This dilemma is reflected in *Case Study 3: Risk is Unexplained*, in which Louise knew that hyperemesis impacted her preterm births, but didn't know why this was happening to her. “I guess I do have a pattern of high-risk pregnancies...first of all, why? I would like to know why do I go through this all the time?” In the first case study,

although Stephanie's mother, who stated her concern that pregnancies being too close together contributed to her daughter's preterm labor, is also puzzled, "I'm just not sure what it is. I don't know. I don't know if it comes from smoking, drinking...I have no idea what exactly it is." Louise also intimates that there is an element of fate to her condition. She did not understand what was happening and did not know what to do. Perhaps it was just her destiny.

The question raised in this paper was, "how does the woman at risk for preterm delivery assess, manage and avoid risk in light of the fact that there is no blueprint for active risk reduction?" The answer is that most women interviewed had difficulty conceptualizing a plan to avoid being at risk for preterm birth. This is a key point, particularly in light of the finding that the women were held responsible, as individuals, for the untoward outcomes of their pregnancies. Their difficulty conceptualizing a plan to avoid risk is also reflected in the challenges faced in the biomedical community. Because, while assessing risk status is a common practice, "risk assessment makes it possible to talk about and seemingly control what is, in fact an unknown medical event for a specific individual" (Handwerker 1994:669). Epidemiological risk calculations do not necessarily translate to a known or understood risk for any given individual, but, like the fate model, they also do not assign blame and responsibility to the mother.

In Louise's explanatory model, it was clear that she had a conscious, value laden desire to reduce harm. There is, however, a difference between "risk"—the likelihood of a bad outcome—and "harm"—the actual ill effect. What became evident was that the doctor's primary goal of reducing *risk* contrasted with the goals of the mother whose primary concern was preventing *harm*. Louise wanted very badly to deliver her baby as

soon as possible. The hyperemesis made her miserable and incapacitated. She knew that if she delivered right away her son would be very small, but she did not believe that being small would be harmful to him. When the physicians spoke to her about the risk, their concern about harm was implicit. Her concern was not with statistical risks, however, but was based on her previous experience in which she did not believe her other two children were “harmed” by being born preterm. In the following comment, the high risk nurse, Denise, describes how some the mothers she cared for would think.

“I had John at 28 weeks and he’s fine, so I’m 28 week now, so it’s okay if I have this baby.” So then I have to tell them that you need to go to 40 weeks. The further along you go, the better. And just because John was okay doesn’t mean that this baby is going to be okay. We’re keeping you to try to prolong the pregnancy and everything I tell you to do or not to do is based on that.

It was evident that the pregnant women were often targeted as being the source of risk, but they could not change most existing epidemiological risk factors during their pregnancies. While, “discourses of risk can . . . construct women and families as responsible for the outcomes of childbearing” (Mackinnon and McIntyre 2006:60), they may actually have no power over those outcomes. In addition, Mackinnon and McIntyre found that, “individual risk discourses intersected with economic and social discourses in ways that forced the women to carry the burden of responsibility for preterm birth prevention, and for the work of managing their household, along with the health work for preterm labor” (2006:66). Their findings aligned with the multiple stressors faced by my informants. These stressors also impacted how they assessed and addressed risk in their day-to-day activities.

I asked the pregnant women I interviewed whether or not they made any changes in their daily routines as a result of being pregnant. Part of the reason for this

question was that Gupton et al. (2001) showed that when women modify their behavior, they lower their perception of risk. The women's agency offered them a sense of control and a perception that their relative risk was lessened because of their actions. Stephanie believed she could affect a change in the outcome of her next pregnancy if she adhered to certain guidelines.

Well if I was actually going to be pregnant again, it's going to be planned. I'm not just going to get pregnant, being naive. I'm going to plan it. I won't have to do nothing. I'm going to chill out, take care of myself, properly. I'm not just going to have no baby, just cause I got lost, caught in the moment, that night (laughs). No more, that's not going to happen. Make sure that my body be right, and I'm ready, you know?

An interesting finding by Heaman et al.(1992:262), when comparing childbirth expectations, was that the woman's perception of how much her pregnancy was at risk was a better predictor than her prenatal risk score. The concept of biomedical rationality is important in this analysis of how risk is framed in relationship to how the woman envisions her role in risk reduction.

“Biomedical rationality includes the mental transformation of people into patients and ultimately into cases—the objects of biomedical care. It also entails the search for biological causes of disease, the diagnosis or reframing of subjective experiences of illness into symptoms and signs that can be measured and prescribed treatment based on objective scientific evidence” (Mackinnon and McIntyre 2006:59). A problem with biomedical rationality, however, is that it “underestimates the self healing capacities of individuals and the influence of their environment” (Mackinnon and McIntyre 2006:59). A risk, with the pervasive use of advanced biomedical technology, is that women come to devalue what they feel, and the way in which that allows them to interpret and trust their body's signals. However, women can be assisted and empowered by being

taught, as Dr. Jones and Dr. Toma suggested, to recognize symptoms that require immediate attention. By drawing upon an embodied vigilance that monitors the messages within, they may avoid domination by “abstract prescriptions that have no synchronicity with the context of their lives” (Williams and Mackey 1999:43). Precious shared an experience that illustrated this embodied vigilance. She commented that the doctors had performed a test for fetal fibronectin that would predict whether or not she was going to deliver soon. The test indicated she would not, but Precious said, “I know my body” and correctly predicted the imminent, preterm birth of her child.

Discussions by most of the health care providers emphasized their collective belief that they had a primary responsibility to intervene to increase the length of gestation for women at risk. Anything that could be done to prolong gestation and save the fetus, intact, should be done. The mother’s behavior was a major focus of these efforts. “Medicine’s unilateral focus on the outcome of pregnancy reflects how the concepts of production and reproduction are confused: the woman is viewed as a ‘vessel’ to produce the ‘product,’ infant” (Williams and Mackey 1999:29).

There needs to be a view that encompasses a wider range of social and cultural values, and expands the definition of success beyond a gestational age at birth. Currently, however, it seems that, “biomedical understandings of population health science construct measurable health outcomes as the only valid means of evaluating health services” (Mackinnon and McIntyre 2006:69). Setting birth as the endpoint ignores a wealth of other concerns that factor into a positive outcome. In this country we place responsibility on the individual for having a successful pregnancy outcome, but that is not the whole story. “The difficulty with individualizing risk is that it negates social

and political effects of biomedical and epidemiological conceptualization on the lives of childbearing women and their families” (Mackinnon and McIntyre 2006:60). One of the great values in anthropological research is the opportunity to examine and interrogate perspectives that are outside the dominant or popular discourses in society. While not ignoring the serious medical morbidities that can occur with an infant born preterm, Mackinnon and McIntyre (2006:69) suggest another way of viewing preterm birth. “What would happen if we shifted our gaze from the outcomes of pregnancy to the celebration of childbearing as a ‘workful’ process? Would we come to value the work performed by these women as they become mothers to the smallest citizens?” (Mackinnon and McIntyre 2006:69). It would have been a welcome change for the pregnant women I interviewed to be congratulated on their success in bringing these little citizens into the world, rather than being judged by friends, family, and practitioners as having somehow failed.

In addition to my key findings about perceptions regarding individual responsibility, stress, and women not knowing why they had premature births, another very intriguing finding was the following. In discussions with women hospitalized for risk of preterm labor, what was notably missing was a sense of “we-ness” or an expressed sense of connectedness with other women experiencing their same problems. When as many as one in every six African American women in Detroit delivers preterm, the commonness of this phenomena might lead to the expectation that an, “all in the same boat” feeling would be reflected in some of their discussions. On the contrary, many stated that they were not aware that this was a problem for African American women. There was far more of an existential dismay, a sense of “why me?” Many felt like the

outsider, the different one, the one who perhaps could not fulfill family, social or cultural expectations to have successful pregnancies. It was concerning to learn that the women did not know that their problems were part of a major national and international dialogue. However, I would like to note here that one of the key aspects of a judgment of immoral behavior, as discussed by Mary Douglas, is that one is rejected from the group. Isolation is an integral aspect of a moral judgment, which can explain, to some degree, their lack of awareness.

This study, explicating explanatory models and value hierarchies, should help to move the research, dialogue and best practices forward. By incorporating these qualitative findings into the multitude of previous research findings on this subject, an opportunity exists to design an exemplary model for intervention. These case studies reconfigure and redress the concept of non-compliance. Complaints about patient non-compliance ignore the life circumstance of the women, including their support systems and lack of common resources such as transportation and childcare. "A great tension emerges between medical professionals recommending behavioral changes and the limits their patients may have in complying with them" (Handwerker 1994:671).

Further, this anthropological analysis provides the opportunity to capture the everyday reality of these African American women's lives, an analysis that contrasts with the biomedical approach of assessments based on pregnancy outcome. Some of the explanatory models integrated and supported the theoretical concept of risk perception emerging from societal standing, but others were more closely related to feminist theory and neoliberalism. A fuller appreciation for the complexity of women's needs and priorities, as well as their desire to do their best in light of societal demands

and their own hierarchies, offers health care providers the opportunity to perform more engaged and comprehensive assessments of women at risk. “Our analysis has shown that current approaches place the burden on the woman and her family instead of treating it as a joint responsibility of governments, communities, employers, institutions, and health professionals” (Mackinnon and McIntyre 2006:70).

In summary, maternal behaviors, stress, and no explanation (or possibly fate) were the three primary explanatory models that emerged from this research. However, there were other perceptions and observations shared by the informants that are important to the analysis of this study. The concept that this was *God’s will* was a thread of conversation woven through many of the discussions by the pregnant women, and their family members. Though not the primary explanation, it was a prevalent theme not only in the case studies, but also among the other pregnant women and families interviewed by me whose discussions but not presented in this work. From the point of view of the providers, education, or a lack thereof, was a key factor in their concept of why African American women were at increased risk. These additional explanations will merit investigation in future studies. In concert with findings from key previous studies of risk perception and pregnant women, four issues emerged in this current study.

First, the perceptions of the multiple causes of risk varied, but the pregnant women, their family members, and the health providers all identified maternal behaviors as a major explanation for preterm delivery.

Second, interventions to prevent preterm birth are assessed differently based on the social location and perspective of the actors. The women were shown to be moral actors whose assessments of risk and harm extended beyond a concern for their

gestational age at delivery, and encompassed their competing and compelling roles as mothers, wives, homemakers and breadwinners. The health care providers, from a biomedical standpoint, more narrowly assessed risk in terms of the impact on the unborn fetus. Among some of the African American providers, there was an acknowledgement of the multiple and complex life circumstances that challenged and compromised the ability of the women to conform to routine medical advice, but these were generally not addressed as a concern requiring intervention.

Third, two types of support were found wanting. The need for a functional and reliable support system, profoundly important for all pregnant women, is essential for those with high risk complications. This type of hands on, physical help was very much lacking for many of the women interviewed in this study. However, they also lacked a sense of “we-ness”. As mentioned earlier, the women often felt alone in their condition. They did not feel that they had a “sisterhood” of support from women experiencing the same problems they were having.

Fourth, stress continues to be the factor that most clearly predicts the disparity in women who will be at risk for preterm birth, and was the explanation that had the highest degree of convergence among the pregnant women in this study. Overwhelmingly, women identified stress as a factor in the onset of preterm labor.

While this study supports and enhances some of the previous findings for women at risk for preterm birth, it extends the research by adding the perspective of African Americans. The specific societal structures that create and sustain racialized and compromised opportunities for African Americans also impact the four factors—maternal behaviors, cultural expectations, support systems and stress—associated with

this discussion of perception of risk for preterm birth. In the concluding chapter of this work, the presentation of the reasons why these structures deserve intense scrutiny and review will offer a new perspective on how this disparity in birth outcomes can be addressed.

CHAPTER 12

CONCLUSION

This study provided an anthropological inquiry into the interaction of multiple conceptualizations and constructions of risk by examining the *at risk* pregnant woman, her mother, her partner, and health care providers. Among these informants, it explored the similarities and differences in where they located risk, and how they assigned responsibility for managing risk and controlling pregnancy outcomes. Additionally, this research framed, from the point of view of the patient, what it meant to be both *at risk* and to be a *source of risk*.

By examining the varying explanatory models of risk, three important issues emerged. First, despite the fact that the pregnant women may have had no control over the onset of preterm labor, all of the informants interviewed assigned primary responsibility for pregnancy outcomes to the women's behavior. Second, the pregnant women and their families did not have an awareness of the structural/racial components of preterm birth. They did not have what I described as a sense of "we-ness", or the knowledge that they were part of a larger group with similar outcomes. Third, the mothers and the health care providers often differed significantly in how they prioritized the needs of the fetus versus other responsibilities; in their perceptions of concepts such as "risk" versus "harm"; and in the importance placed on gestational age at delivery. Finally, these findings suggest the need for developing new ways to assess and address preterm birth through alternative models and best practices.

The original concept for this study began with a concern about why African American women and their families were so disproportionately affected by preterm birth.

Although my in depth research into the physical and biological meanings of race failed to identify a racial explanation for this health disparity, the continued emphasis on racialized pregnancy outcomes has advanced popular discourses that focus on individual behavior, and genetic and cultural predisposition. Biological explanations continue to promote a view that stigmatizes African American women as being inherently deficient, despite the fact that human biological variation is not racially patterned (Frank 2002). In both academic and public discourse, structural barriers, structural inequalities, and structural racism rarely rise to the surface of the flood of data that implicates a multitude of other factors. In this concluding chapter, sociologist Rachel Sanders' (2012) treatment of how racialized structures result in the embodiment of illness, is expanded to explain the how preterm birth among African Americans must be viewed within the larger social context of their lived experience.

Assigning Responsibility

How responsibility is assigned varies not only by the individual actors, but by the models that are used to understand and explain illness. The models employed directly impact how conditions such as preterm birth are assessed and addressed. Traditionally, the biomedical model emphasizes *endogenous* pathways of pathogenesis. The endogenous pathways are the “processes of disease acquisition that originate from within a person and thus are not attributable to any external or environmental factors” (Sanders 2012:8). This biomedical individualism assumes that problems of population health are matters of lifestyle and faulty genes (Krieger and Smith 2004). Conversely, “an embodied approach promotes testing hypotheses to ascertain if the observed disparities are a biological expression of racial discrimination, past and present” (Krieger

2004:350). A renewed and revised focus on preterm birth and African American women would have to avoid the “reductive analysis of disease distribution” (Sanders 2012:8) that highlights the lifestyle model, where risky health behaviors result in outcomes in these endogenous pathways.

According to Nancy Kreiger, our “bodies tell stories about—and cannot be divorced from—the conditions of our existence. Bodies tell stories that people cannot or will not tell, either because they are unable, forbidden or choose not to tell” (Kreiger 2004:350). *Embodiment* is a concept “referring to how we literally incorporate, biologically, the material and social world in which we live, from in utero until death” (Kreiger 2004: 352). Kreiger emphasizes both the conscious and unconscious embodiment of social conditions. If African American women are biologically incorporating the circumstances of the lives, then the persistence of preterm labor and delivery can be explained. However, because embodiment can be unconscious, the women may not be able to identify the source of their problems.

Maternal behaviors were a frequent point of discussion in this study, many times alluding to personal irresponsibility or personal moral failure. When individual-level explanations are advanced, focus is deflected away from the impact of abiding social structures (Sanders 2012:3). Yet, these very social structures help to explain the scientific accounts of preterm labor.

Structural violence, often resulting from structural disadvantage, describes the systematic ways in which social structures harm or otherwise disadvantage individuals. Paul Farmer defines it as “mechanisms by which social forces, ranging from poverty to racism, become embodied as individual experience” (Farmer 1996:261-262). Structural

violence (unlike behavioral violence) is subtle, often invisible, and usually has no one specific person who can or will be held responsible. A key aspect is that it is often hard to see. There are no knives, no bullets, and no bleeding wounds, yet serious harm occurs. “Structural violence may lead to death, but just as often it may manifest in the form of outcomes that are not as positive as they otherwise could be, or should be” (Structural Violence 2012).

With structural violence, the cycle of inequality is self-perpetuating. The book *The New Jim Crow*, by Michelle Alexander (2010) emphasizes a point made over a decade ago by Bonilla Silva. “Reproduction of a racial hierarchy in American society must be explained not by reference to a long distant past, but in relation to its contemporary structure” (Bonilla Silva 1996: 476). And this structure, as Mary Douglas has theorized, places certain groups at risk and others in the position of causing risk. “Cultural analysis is a countervailing vision which warns what categories in each kind of culture are most likely to be at risk, who will be sinned against, and who will be counted as sinner in exposing others to risk.” She too, emphasized that processes that systematically select certain groups for recrimination are not outdated. “There is nothing old-fashioned or exclusively primitive about social stereotyping” (Douglas 1990:15).

While pregnancy-specific stress, and racism-specific stress were both linked to the disparities in birth outcomes, methods for addressing and ameliorating these factors were not forthcoming. The heavy emphasis on maternal behaviors did not take into account the extensive research findings that specific types of stress are a likely explanation for the disparities in preterm birth. The findings from Mackinnon and McIntyre suggest that, “risk discourses exert social control over pregnant women and

result in fear, guilt, feelings of being judged or punished, and an overwhelming sense of personal responsibility for preventing preterm birth” (Mackinnon and McIntyre 2006:57).

In general, there is a culturally constructed *reproductive imperative* for women throughout the world. This arises from the obvious fact that only women can bear children, but aspects such as when, how, and how many, are highly culturally defined. More importantly, how a woman fulfills the cultural expectations regarding reproduction greatly impacts her status, and position in society. Those societal norms will determine whether she is stigmatized, or marginalized on one hand, or held in high esteem and rewarded on the other. Carrying through a “successful” pregnancy has been difficult for a significant percent of African American women, despite extensive studies and interventions on their behalf. Charlene Davison, the midwife interviewed in this study, summarized very succinctly what was missing for many of these women. “I think that if they just knew, ‘If I’m okay, this baby inside of me will be okay’.” There is a great need, therefore, to “step outside the biomedical paradigm and to embrace the notion that women who have healthy bodies and healthy lives are those who are most likely to have healthy babies” (Williams and Mackey 1999:43-44).

Lack of Awareness of Social/Structural Causes

Several explanatory models were offered by the informants in this study, but only once, during the 25 interviews, was racism, by name, suggested as mediator in the phenomenon of preterm birth. Racism specific stress, and its impact on pregnancy outcomes for African American women has been well documented in the literature for over a decade (Klonoff 1999; Giscombé and Lobel 2005; Nuru-Jeter 2008), yet, with

one exception, neither the pregnant women, their families nor the health care providers included racism as a factor in their perceptions of sources of risk.

For low-income African American women, the impact of racism is most profound on the macro or institutionalized level. Poor housing, environmentally unhealthy neighborhoods, violent communities, unsafe streets, poor nutrition and food options, poor school and educational opportunities, poor job opportunities, poor recreational choices and inadequate transportation all result in impeded life chances, and compromised health. “The notion of embodiment as a biological expression of social conditions rightly figures the body as a sign of social disparity that may substitute for or corroborate verbal testimony to racial inequality” (Sanders 2012:8). The stress women experience through all these forms of institutionalized racism is often not appraised as being the result of racist and racialized structures. Yet, they suffer mightily from this stunting of opportunity.

For African American women higher on the socioeconomic ladder, those who are college educated, with professional careers, living in healthy neighborhoods, who practice good nutrition and get adequate exercise, the impact of racism is often the individualized, or personally mediated type.

“A structural conception of racism, or racial disadvantage as perpetuated through the dynamic interaction of various social institutions is crucial to the examination and eradication of racial health disparities . . .” (Sanders 2012:20). The implication of structural violence “born out in black bodies” (Sanders 2012:14) is that they are more prone to experience preterm birth.

Differing Priorities, Differing Concepts of “Risk” and “Harm”

All of the mothers interviewed expressed concern about not neglecting their other responsibilities because of the pregnancy. Many of the health care providers recognized the difficulty of prescribing bedrest to a woman with responsibilities for her other children and home, but that recognition did not translate into a way to help the mothers. Concerns about being confined revealed a number of significant differences in the priorities of the mothers and their health care providers. For example, mothers considered “risk” and “harm” to be two different concerns. Those who had had a previous preterm birth which resulted in a healthy child did not consider prematurity “dangerous,” while physicians were concerned with maximizing gestational age. Mothers, needing to get back to myriad responsibilities at home, wanted to reach a gestational age that meant the baby would probably be okay. For physicians, the unborn baby was the only child that mattered; for the mother, the baby was one of several children whose needs must be considered.

The National Institutes of Health established the National Center for Advancing Translational Sciences (NCATS) on December 23, 2011 “to catalyze the generation of innovative methods and technologies that will enhance the development, testing, and implementation of diagnostics and therapeutics across a wide range of human diseases and conditions” (NCATS 2012). The program, through the funding of clinical and translation science awards, encourages collaboration among investigators to find practical solutions for complex health challenges. It is a cross disciplinary approach translating bench science into applications at the bedside or into interventions that benefit the greater community.

The idea of applying bench science to community health problems is both laudable and necessary. Just as technological and pharmaceutical advances that meet the standards for safety and efficacy should be made available to the public in a timely manner, so should important research findings in the social sciences that contradict or enhance current understandings of health disorders.

Because pregnancy-specific stress (Lobel et al. 2008) is associated with preterm birth, interventions that could moderate that impact by relieving high risk pregnancy worries would be indicated. While this study was not designed to investigate depressive symptoms, the six pregnant participants who completed the Edinburgh Depression Scale (Appendix D) all scored between 11 and 17, a level indicating the presence of distress. A discussion between provider and patient that included directly addressing what was known about the patient's pregnancy risks, including the fact that her status as an African American was a component in that risk assessment, could help to allay some feelings of guilt and focus interventions on the more mutable aspects of risk. Neither the providers nor the patients indicated that there was a co-negotiation of risk that preceded or accompanied their therapeutic interactions. The doctors and midwife shared extensively regarding the teaching methods they engaged to diminish the likelihood their patients would continue the pattern of preterm delivery, but the patients' needs were not given equitable weight in this process. Although the challenges faced by patients were not trivialized by providers, there was not an active engagement of a process to arm women, and those in their support network, with methods to address stress.

While racism seems like a formidable and intractable foe, one that cannot be destroyed, there are ways that the impact of racism can be mitigated. In Michigan, a program designed to address the impact of racism on birth outcomes is showing some positive results. The Genesee County Racial and Ethnic Approaches to Community Health (REACH) coalition has been making strides in both analyzing and confronting racism specific stress on birth outcomes (Carty et al. 2011). The program, a community based participatory research (CBPR) partnership is designed to address social determinants of health. The authors note that there is a dearth of information about how racism impacts health disparities at the local level. The focus in Genesee and Saginaw counties in Michigan is to “assess how a sustained community intervention to reduce racism and infant mortality influenced knowledge, beliefs, and experiences of racism and to explore how perceived racism is associated with self-rated birth outcomes” (Carty et al. 2011:84). The results of their early analysis was that racism related experiences were marginally associated with lower birth weights, but also that the participants who received intervention had a better awareness of the enduring impact of racism when compared to non-intervention participants (Carty et al. 2011). While this study has a limited scope, it is an important first step towards developing a community understanding of how social circumstances can affect pregnancy (and health in general), and may hold promise for the replication of its results in other communities throughout the country.

The concept of translational science can be applied to qualitative studies. In this instance, the research finding that the stress of structural racism plays a significant role in the pregnancy outcomes for black women should be applied to the development of

interventions that can combat the impact of these structures, and diminish the number of infants born preterm. A newer model of health care, described as “Centering” features a comprehensive care program that may address some of the particular needs of women at risk for preterm birth.

Alternative Models

Centering, the health model in which the focus of care is broadened to include support provided through small groups, can facilitate connectedness. With Centering, the health outcome goals for women at risk include increased birth weight and greater gestational age at delivery (Centering Healthcare Institute).

According to the Centering Health Institute, in a study conducted by Yale University of 1,047 women who participated in centering groups, there was a 33 percent reduction in preterm births (Centering n.d.). Centering offers a model of group health care, where participants have an initial individual assessment by health care providers, which is followed by regularly scheduled group sessions. These group sessions are designed to build a support group through which health options are explored, and wisdom and experience are shared. With sessions such as these, the isolation that women in my study experienced, in not realizing there were many others having similar experiences, would be alleviated. These Centering groups are described as “lively, interactive and patient centered.” A more detailed description of the Centering Health Group is found in Appendix G.

The 11th Street Family Health Service in Philadelphia, funded by a grant from the Robert Wood Johnson Foundation, is a model that has much in common with the Centering philosophy, by providing a “centralized location to receive health and

wellness services” (Nursezone.com). The providers there work with women from pregnancy until their child is two years old, giving them the extra support that is so needed by program participants. An example of how a program like this could be helpful to women who feel lost in the maze of the health care system, can be drawn from a statement made by Louise. Louise, who suffered with severe hyperemesis, showed the disconnect between some patients and their health care providers by her statement, “I can’t keep track with which one is actually my official doctor because doctors come in for this and that, other doctors come in for something totally different.” This would also address the concerns expressed by Handwerker (1994) who described the experience of poor, and especially, black women in the health care system, from having to spend long hours awaiting exams in public clinics, to being stigmatized with the label of high risk. As with Centering, the women would receive both specialized and personalized care.

Another model, a program instituted in Cuba, offers an alternative approach that could be successful in lowering the rate of preterm birth and infant mortality in the United States. This innovation, proven effective in a country that once had an infant mortality rate far worse than the United States, is the implementation of Maternity Homes. In 1962 Cuba had a maternal mortality rate of 117.9 per 100,000 and an infant mortality rate of 41.5 per 1,000 births (Gorry 2011). At that time more than 80 percent of the women did not deliver in hospitals because they lived in rural locations, with poor roads, difficult mountainous terrain and poor transportation options, and could not travel the long distances to the nearest birthing facility. When complications occurred, women and their infants would die trying to get to medical services. Maternity Homes (*Hogar*

Materno) were started to address the needs of pregnant women, and they now they exist in every municipality in Cuba (Gorry 2011).

In the beginning, the maternity homes, constructed close-by to hospitals, served to relocate women from rural sites, and the women would then reside in these facilities until they delivered. The program was a success. By 1989, 98 percent of Cuban women delivered in a hospital, and the maternal mortality and infant mortality rates had dropped by two thirds (Gorry 2011). In the 1990's, when an economic and political crisis led to a scarcity of food, an emphasis began on providing nutrition and diet services. Although the maternity homes were primarily residential facilities, women could also come for food and services as outpatients. "*La comida*" (the food) is one of the reasons many women give when asked why they enjoy the program (Gorry 2011).

Currently, any woman meeting high risk guidelines, established in cooperation with UNICEF, may be admitted for treatment in a maternity home setting. Care in the maternity homes is multidisciplinary. The comprehensive care team includes an obstetrician, psychologist, clinical nutritionist and dietician, internist, dentist and fitness trainer. Social workers and psychologists work with the women to resolve social issues in the home and address sources of stress. There is also an extensive education program for childbirth, breast feeding, family planning, HIV prevention and parenting (Gorry 2011).

As of 2010, the infant mortality rate in Cuba was 4.5 per 1000 births (Gorry 2011), lower than the rate of 6.14 in the United States. The maternity homes that currently exist in the United States are primarily for pregnant teens who have nowhere to go, or to provide services for women as an alternative to abortion. The type of

comprehensive care offered as described in the maternity homes in Cuba is not now available for U.S. families.

Best Practices

The cost of preterm births, individually and on a macro level, is staggering. Although structural racism, and the role it plays in preterm birth, cannot be reversed in the short span of a pregnancy, this study reveals several areas where modifications in antenatal practices can bring about an improvement in outcomes. Through a co-negotiation of risk, practices and interventions are needed that (1) reduce pregnant women's feelings of isolation and helplessness, equipping them to be proactive in managing their pregnancies; (2) engage pregnant women and their families as active participants in the design of treatment plans, recognizing factors such as differing perceptions of risk and harm, and maintaining an awareness of the family's conflicting priorities and needs; (3) explore treatment options with a recognition of the patients' day to day realities, so that the treatments potentially reduce, instead of increase stress; and (4) understand that traditional hospitalization may pose a risk to families and that alternative settings for care and support need to be explored. "Health professionals, who communicate about risk, need to understand the perspectives of those whom they advise, and to appreciate the influence of personal values, orientation toward the future, and culture upon any risk appraisal, lay or scientific" (Heyman 1998:1305).

Replicating a program in the United States such as the one in Cuba may seem an insurmountable task, but the benefits of such a program could potentially save the country billions in health care cost over the next decade and substantially reduce the infant mortality and preterm birth rate. The centering programs, already in the United

States, also offer promise. The stories told in this study by the providers and patients indicated that the serious psychosocial, educational, nutritional and environmental challenges faced by many women affected by preterm birth could be addressed by interventions such as these. Research that has been conducted nationwide, by multiple disciplines, has not yet discovered an effective method for decreasing the disparity in preterm birth for African Americans, but the field of anthropology is ideally suited to inform the construction of community based projects of this nature. They would best be accomplished, however, as a multidisciplinary endeavor.

The field of anthropology has its roots in studying the relationship between populations and the societies in which they live. Today we still struggle with a health problem that has stubbornly endured despite decades of research in multiple disciplines to uncover and address the causes. The combined efforts from the fields of Medical Anthropology, Epidemiology, and Public Health (Inhorn 1995) may help to recast the role of our society in health disparities in a manner not fully accomplished by any one of the disciplines alone. The findings of this study support such a possibility. The African American families and health care providers interviewed for this research shared explanatory models of risk that assigned primary responsibility for pregnancy outcomes to the women's behavior. Their models did not acknowledge the moral hierarchies, the multiple stressors, or the structural racism that impacted every aspect of the women's lives. The conclusions of this study indicate that effective interventions must address these factors. An interdisciplinary effort which recognizes all aspects of the complex issue of preterm birth, including how risk is perceived by those who are most affected by

prematurity, may succeed in making the current high rates of disparity something that will only exist in medical and anthropological history.

APPENDIX A

Research Informed Consent

Title of Study:

Prematurity and Perceptions of Risk in the African American Family

Principal Investigator (PI): Gwendolyn S. Norman, RN, BSN, MPH
 Department of Anthropology
 (313) 577-2375

Purpose

You are being asked to be in a research study of how African American women who have had a previous preterm infant, and are now at risk for another preterm delivery, understand the meaning of that risk. This study is being conducted at Wayne State University at Hutzel Women's Hospital. The estimated number of study participants to be enrolled at Wayne State University is about 12 pregnant women and their families. **Please read this form and ask any questions you may have before agreeing to be in the study.**

A full term pregnancy last 40 weeks, and infants born before 37 weeks are considered preterm. Babies who weigh less than 5½ pounds are considered low birth weight, and the most common reason for babies to be have low birth weight is because they are born preterm. Infants who are born preterm are more likely to have serious health problems than babies born full term. Understanding and trying to prevent preterm birth is one of the most challenging problems facing health care providers. One thing we know is that African American women are more likely to deliver premature or low birth weight infants than any other group in this country. Nationally, about 6% of all babies are born less that 2500 grams, however among African American women the rate is over 13%. There are many reasons why physicians believe women may be at risk for preterm delivery, but the purpose of this study is to learn what pregnant women who have had preterm babies, understand and believe about their risk.

Study Procedures

If you agree to take part in this research study, you will be asked to participate in two interviews. The first will be conducted at your bedside, and the second will be conducted either at your bedside, at your home, or another place of your choosing if you are discharged before you deliver. Each interview should take approximately one hour. During the first interview you will be asked questions regarding your current pregnancy, your pregnancy history, what being at risk means to you, and a to complete a questionnaire about any experiences you have had with racism. During the second interview you will be asked more about the health of you and your family, and to complete questionnaires regarding depression and how you rate your health. The interviews will be recorded on an audiotape. At any time during either of the interviews you will be free to decide not to continue the interview, or to choose not to answer any question you are uncomfortable with. The information collected in these interviews will be kept confidential. The interview tapes, and notes taken will be identified with a unique code number, and not your name or any other personal identifiers. At the end of the study, once the taped interviews have been transcribed, the recordings will be destroyed.

Benefits

The possible benefits to you for taking part in this research study are that you may enjoy discussing issues related to your pregnancies and your understanding of your risks. Additionally, information from this study may benefit other people now or in the future.

Risks

By taking part in this study, you may experience the following risks. You may feel uncomfortable discussing certain subjects. You are free at any time during the interview to end the discussion if you decide you no longer wish to participate. You also have the option to choose not to share information about you that you feel is very personal or private, such as information regarding abuse or criminal activities. Whether you choose to discuss such information or not, all information you share will be kept strictly confidential.

There may also be risks involved from taking part in this study that are not known to researchers at this time.

Alternatives

Your alternative is to choose not participate.

Study Costs

Participation in this study will be of no cost to you.

Compensation

For taking part in this research study, you will be paid for your time and inconvenience. You will receive \$25.00 cash at the end of each of the two interviews, for a total of \$50.00.

Confidentiality

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Information that identifies you personally will not be released without your written permission. However, the study sponsor, the Human Investigation Committee (HIC) at Wayne State University, or federal agencies with appropriate regulatory oversight [e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.] may review your records.

When the results of this research are published or discussed in conferences, no information will be included that would reveal your identity.

The audiotape recordings of you will be used for research purposes, and your identity will be protected or disguised. Your tapes will only be identified by a unique code number, and only the investigator and the transcriber will have access to the tape. At the end of the study the tapes will be destroyed.

Voluntary Participation/Withdrawal

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you decide to take part in the study you can later change your mind and withdraw from the study. You are free to only answer questions that you want to answer. You are free to withdraw from participation in this study at any time. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are entitled to receive.

The PI may stop your participation in this study without your consent. The PI will make the decision and let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study

Questions

If you have any questions about this study now or in the future, you may contact Gwendolyn S. Norman, RN at the following phone number (313) 577-2375. If you have questions or concerns about your rights as a research participant, the Chair of the Human Investigation Committee can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

Consent to Participate in a Research Study

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

Signature of participant / Legally authorized representative *

Date

Printed name of participant / Legally authorized representative *

Time

Signature of witness**

Date

Printed of witness**

Time

Signature of person obtaining consent

Date

Printed name of person obtaining consent

Time

*Remove LAR reference if you don't intend to consent participants that have or may have a LAR.

**Use when participant has had this consent form read to them (i.e., illiterate, legally blind, translated into foreign language).

Signature of translator

Date

Printed name of translator

Time

Continue to HIPAA Authorization on next page

HIPAA Authorization

A federal regulation, known as the “Health Insurance Portability and Accountability Act (HIPAA)” gives you certain rights concerning the use and disclosure (sharing with others) of your Protected Health Information (PHI). This regulation provides safeguards for the privacy and security of your information. Your permission (authorization) is required for the use and sharing of any protected health information collected as part of this research study. If you are not willing to sign this authorization to use and/or disclose your PHI by the research team, you will not be eligible to take part in this research study.

The principal investigator (PI) team will use your medical records and information created or collected as part of this research study. Your PHI is important for the PI in order to collect information about you during the study, to be able to contact you if needed, and to provide treatments to you during the study, if required. The PI may send out your study related health information to the sponsor or other entities involved in this study.

Your medical records, which may contain information that directly identifies you, may be reviewed by representatives from groups identified below. The purpose of these reviews is to assure the study is being conducted properly, that data is being obtained correctly or for other uses authorized by law. These reviews occur at the study site or in the PI’s research office and can take place anytime during the study or after the study has ended.

The PHI that will be “USED” for this research includes the following: name, address (street address, city, state and zip code), elements of dates, telephone numbers, medical record number, and any unique identifying numbers or characteristics or code.

The PHI that will be “DISCLOSED” or shared with others for this research includes the following: y unique identifying numbers or characteristics or code.

Your study information may be **used** or **shared** with the following people or groups:

- The PI, co-investigators, and key personnel of WSU associated with the research project
- WSU’s HIC and the Institutional Review Boards (IRB)
- Federal agencies with appropriate regulatory oversight (e.g., FDA, OHRP, OCR, etc.) may review your records

Once your information has been released according to this Authorization, it could be released again and may no longer be protected by the HIPAA regulations.

This Authorization does not expire. The research team may need to correct it or provide missing information about you even after the study has ended, and your medical records may be needed to assist in this process.

- During your participation in this research project you will not be able to access that part of your medical record involved in the research. This will be done to prevent the knowledge of the research results from affecting the reliability of the project. Your

information will be available to the treating physician should an emergency arise that would require for him/her to know this information to best treat you. You will have access to your medical record when the study is ended or earlier, if possible. The PI is not required to release research information that is not part of your medical record.

You may withdraw (take back) your permission for the **use** and **disclosure** of your PHI for this research at anytime, by **writing** to the PI at the address on the first page of this form. Even if you withdraw your permission, the PI for the research project may still use your PHI that was collected prior to your written request if that information is necessary to the study. If you withdraw your permission for use of your PHI, you will also be withdrawn from the research project. Withdrawing your authorization **will not** affect the health care that will be provided by the Detroit Medical Center and/or the WSU School of Medicine Practice Plans.

Authorization to use and disclose PHI

- ❖ By signing this document, you are authorizing the PI to **use** and **disclose** PHI collected about you for the research purposes as described above.

Signature of participant

Date

Printed name of participant

- ❖ For participants unable to give Authorization, the following individual is acting on behalf of the research participant (e.g., children, mentally impaired, etc.).

Signature of authorized representative

Date

Printed name of authorized representative
Relationship to the participant

Signature of person obtaining Authorization

Date

Printed name of person obtaining Authorization

Time

APPENDIX B

Research Informed Consent

Title of Study:
Prematurity and Perceptions of Risk in the African American Family

Family Member Consent form

Principal Investigator (PI): Gwendolyn S. Norman, RN, BSN, MPH
Department of Anthropology
(313) 577-2375

Purpose

You are being asked to be in a research study of how African American women who have had a previous preterm infant, and are now at risk for another preterm delivery, understand the meaning of that risk. You are being asked to participate in this study because of your relationship to a woman who has had a preterm baby. This study is being conducted at Wayne State University at Hutzel Women's Hospital. The estimated number of study participants to be enrolled at Wayne State University is about 12 pregnant women and their families. **Please read this form and ask any questions you may have before agreeing to be in the study.**

A full term pregnancy last 40 weeks, and infants born before 37 weeks are considered preterm. Babies who weigh less than 5½ pounds (2500 grams) are considered low birth weight, and the most common reason for babies to have low birth weight is because they are born preterm. Infants who are born preterm are more likely to have serious health problems than babies born full term. Understanding and trying to prevent preterm birth is one of the most challenging problems facing health care providers. One thing we know is that African American women are more likely to deliver premature or low birth weight infants than any other group in this country. Nationally, about 6% of all babies are born less than 2500 grams, however among African American women the rate is over 13%. There are many reasons why physicians believe women may be at risk for preterm delivery, but the purpose of this study is to learn what pregnant women who have had preterm babies, and their families, understand and believe about their risk.

Study Procedures

If you agree to take part in this research study, you will be asked to participate in one interview that will last 30-60 minutes at a location of your choosing. The interview will be recorded on an audiotape. During the interview you will be asked questions about your own beliefs about risk in pregnancy. At any time during the interviews you will be free to decide not to continue the interview, or to choose not to answer any question you are uncomfortable with. The information collected in these interviews will be kept confidential. The interview tapes, and notes taken will be identified with a unique code number, and not your name or any other personal identifiers. At the end of the study, once the taped interviews have been transcribed, the recordings will be destroyed.

Benefits

As a participant in this research study, there may be no direct benefit for you; however, information from this study may benefit other people now or in the future.

Risks

There are no known risks at this time to participation in this study

Alternatives

Your alternative is to choose not to participate.

Study Costs

Participation in this study will be of no cost to you.

Compensation

For taking part in this research study, you will be paid for your time and inconvenience. You will receive \$25.00 cash at the end of the interview.

Confidentiality

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Information that identifies you personally will not be released without your written permission. However, the study sponsor, the Human Investigation Committee (HIC) at Wayne State University, or federal agencies with appropriate regulatory oversight [e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.] may review your records.

When the results of this research are published or discussed in conferences, no information will be included that would reveal your identity.

The audiotape recordings of you will be used for research purposes, and your identity will be protected or disguised. Your tapes will only be identified by a unique code number, and only the investigator and the transcriber will have access to the tape. At the end of the study the tapes will be destroyed.

Voluntary Participation/Withdrawal

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you decide to take part in the study you can later change your mind and withdraw from the study. You are free to only answer questions that you want to answer. You are free to withdraw from participation in this study at any time. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are entitled to receive.

The PI may stop your participation in this study without your consent. The PI will make the decision and let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study

Questions

If you have any questions about this study now or in the future, you may contact Gwendolyn S. Norman, RN at the following phone number (313) 577-2375. If you have questions or concerns about your rights as a research participant, the Chair of the Human Investigation Committee can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

Consent to Participate in a Research Study

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

Signature of participant

Date

Printed name of participant

Time

Signature of witness**

Date

Printed of witness**

Time

Signature of person obtaining consent

Date

Printed name of person obtaining consent

Time

APPENDIX C**Research Informed Consent**

Title of Study:

Prematurity and Perceptions of Risk in the African American Family

Provider Consent form

Principal Investigator (PI):

Gwendolyn S. Norman, RN, BSN, MPH
Department of Anthropology
(313) 577-2375**Purpose**

You are being asked to be in a research study of how African American women who have had a previous preterm infant, and are now at risk for another preterm delivery, understand the meaning of that risk. You are being asked to participate in this study because of you are a practitioner who provides care for women who have had this experience. This study is being conducted at Wayne State University at Hutzel Women's Hospital. The estimated number of study participants to be enrolled at Wayne State University is about 12 pregnant women and their families. In addition 6 health care providers will also be enrolled. **Please read this form and ask any questions you may have before agreeing to be in the study.**

African American women are more likely to deliver premature or low birth weight infants than any other group in this country. Nationally, about 6% of all babies are born less than 2500 grams, however among African American women the rate is over 13%. There are many reasons why physicians believe women may be at risk for preterm delivery, but the purpose of this study is to learn what pregnant women who have had preterm babies, their families, and health care providers understand and believe about their risk.

Study Procedures

If you agree to take part in this research study, you will be asked to participate in one interview that will last 30-60 minutes at a location of your choosing. The interview will be recorded on an audiotape. During the interview you will be asked questions about your own understanding and experiences regarding risk in pregnancy. At any time during the interviews you will be free to decide not to continue the interview, or to choose not to answer any question you are uncomfortable with. The information collected in these interviews will be kept confidential. The interview tapes, and notes taken will be identified with a unique code number, and not your name or any other personal identifiers. At the end of the study, once the taped interviews have been transcribed, the recordings will be destroyed.

Benefits

As a participant in this research study, there may be no direct benefit for you; however, information from this study may benefit other people now or in the future.

Risks

There are no known risks at this time to participation in this study

Alternatives

Your alternative is to choose not to participate.

Study Costs

Participation in this study will be of no cost to you.

Compensation

For taking part in this research study, you will be paid for your time and inconvenience. You will receive \$25.00 cash at the end of the interview.

Confidentiality

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Information that identifies you personally will not be released without your written permission. However, the study sponsor, the Human Investigation Committee (HIC) at Wayne State University, or federal agencies with appropriate regulatory oversight [e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.] may review your records.

When the results of this research are published or discussed in conferences, no information will be included that would reveal your identity.

The audiotape recordings of you will be used for research purposes, and your identity will be protected or disguised. Your tapes will only be identified by a unique code number, and only the investigator and the transcriber will have access to the tape. At the end of the study the tapes will be destroyed.

Voluntary Participation/Withdrawal

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you decide to take part in the study you can later change your mind and withdraw from the study. You are free to only answer questions that you want to answer. You are free to withdraw from participation in this study at any time. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are entitled to receive.

The PI may stop your participation in this study without your consent. The PI will make the decision and let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study

Questions

If you have any questions about this study now or in the future, you may contact Gwendolyn S. Norman, RN at the following phone number (313) 577-2375. If you have questions or concerns about your rights as a research participant, the Chair of the Human Investigation Committee can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

Consent to Participate in a Research Study

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

Signature of participant

Date

Printed name of participant

Time

Signature of witness**

Date

Printed of witness**

Time

Signature of person obtaining consent

Date

Printed name of person obtaining consent

Time

APPENDIX D

EDINBURGH DEPRESSION SCALE*

Also known as the Edinburgh Postnatal Depression Scale (EPDS)*

INSTRUCTIONS:

ADD THE NUMBER NEXT TO EACH CIRCLE THAT HAS BEEN FILLED IN. THIS IS THE TOTAL SCORE. SEE ALSO RANGE OF SCORES ON THE EDS.

1. I have been able to laugh and see the funny side of things:

- 0 As much as I always could
- 1 Not quite as much now
- 2 Definitely not so much now
- 3 Not at all

2. I have looked forward with enjoyment to things:

- 0 As much as I ever did
- 1 Rather less than I used to
- 2 Definitely less than I used to
- 3 Hardly at all

3. I have blamed myself unnecessarily when things went wrong:

- 3 Yes, most of the time
- 2 Yes, some of the time
- 1 Not very often
- 0 No, never

4. I have been anxious or worried for no good reason:

- 0 No, not at all
- 1 Hardly ever
- 2 Yes, sometimes
- 3 Yes, very often

5. I have felt scared or panicky for no very good reason:

- 3 Yes, quite a lot
- 2 Yes, sometimes
- 1 No, not much
- 0 No, not at all

6. Things have been getting on top of me:

- 3 Yes, most of the time I haven't been able to cope at all
- 2 Yes, sometimes I haven't been coping as well as usual
- 1 No, most of the time I have coped quite well
- 0 No, I have been coping as well as ever

7. I have been so unhappy that I have had difficulty sleeping:

- 3 Yes, most of the time
- 2 Yes, sometimes
- 1 Not very often
- 0 No, not at all

8. I have felt sad or miserable:

- 3 Yes, most of the time
- 2 Yes, quite often
- 1 Not very often
- 0 No, not at all

9. I have been so unhappy that I have been crying:

- 3 Yes, most of the time
- 2 Yes, quite often
- 1 Only occasionally
- 0 No, never

10. The thought of harming myself has occurred to me:

- 3 Yes, quite often
- 2 Sometimes
- 1 Hardly ever
- 0 Never

* Murray & Cox 1990 * Cox, Holden & Sagovsky 1987

EDINBURGH DEPRESSION SCALE*
Also known as the Edinburgh Postnatal Depression Scale (EPDS)*
Range of EDS Scores

This information is offered as a guide only.

Remember that the EDS scores apply to the *last seven days*. Use the guide below in relation to the most recent EDS.

Scores

0–9 When scores are in this range this may indicate the presence of some symptoms of distress that may be short-lived and are not likely to interfere with day to day ability to function at home or at work. However if these symptoms have persisted more than a week or two, further enquiry is warranted as to the cause

10–12 Scores within this range indicate presence of symptoms of distress that may be discomforting. We suggest that you repeat the EDS in 1- 2 weeks time for women scoring in this range and if the scores increase to above 12 assess further and consider referral to a mental health specialist or general practitioner for review.

13 + Scores above 12 require further evaluation and possible referral to a perinatal mental health specialist. Repeat the EDS at intervals to monitor progress

APPENDIX E

Code Frequencies

Explanation Codes
Age-4
Attitude-2
Causality Unknown-10
Denial of Risk-4
Diabetes-1
Gender of fetus-2
Genetics-7
High Blood Pressure-4
Infection-3
Irresponsibility-11
IVF-1
Lack of Education-15
Lack of Prenatal Care-4
Lack of Resources-6
Mother/drugs-6
Mother/no support-11
Mother/stress-32
Multiple Medical-4
Normative-9
Needs Pampering-6
Nutrition-16
Pregnancy Interval-15
Prevention-16
Racism-2
Sexual Activity-2
Treatment failure/no treatment-9
Work so hard-19

Environment Codes
Living environment- 20
Poor Neighborhood-3
Safe environment-3

Personhood Codes
Motherhood-14
Moral/Ideal self-28
Self-esteem-6
Responsibility of Mother-13
Depression/suicide-6
Cultural expectations-4

Family Codes
Family Support-36
Family Relationships: Negative Impact-25
Family Relationships: Positive Impact-9
Family History of Prematurity-6
Role of father-7

Spiritual Codes
God-7
God will provide-3
Role of Religion-10
Spiritual Crisis-4
Infant/fetal death-21

Medical Codes
Doctors as authorities-10
Doctors don't know-6
Doctor-Patient Relationship-11
Good Pregnancy Outcome-9
Medical terminology and treatment-31
Noncompliance-4
Role of Provider-12
Safer in Hospital-14
Lack of Knowledge-11
Bedrest-12

Risk Codes
High risk means life style change-21
Meaning of high risk-6
I know my body-7
Illness impact-25
Impact of prematurity-5
Risk factors-10
Risk Taking-2
Risky behaviors-4

Race Codes
Race-11
Race based care-4
Racism-11

APPENDIX F

Kessner Index

Kessner Index: The Kessner Index is a classification of prenatal care based on the month of pregnancy in which prenatal care began, the number of prenatal visits and the length of pregnancy (i.e. for shorter pregnancies, fewer prenatal visits constitute adequate care.) _

Kessner Index Measurement Definitions:

Adequate: Care that began within the first trimester and included an average of at least one or two additional prenatal visits per month of gestation, depending on the length of gestation.

Intermediate: Care that began during the second trimester of pregnancy with correspondingly fewer visits, or began during the first trimester but with fewer visits than would be appropriate for the length of gestation.

Inadequate: When no care was received or if care began during the third trimester. It is also inadequate if care began during the first or second trimester but less than five visits occurred, when the length of gestation was 34 weeks or more. When the length of gestation was less than 34 weeks, care is defined as inadequate when care began during the first or second trimester but a number of visits less than four occurred, that number depending on the actual weeks of gestation.

Source: 2009 Michigan Resident Birth File, Vital Records & Health Data Development Section, Michigan Department of Community Health <http://www.mdch.state.mi.us/pha/osr/natality/tab1.8perc.asp>

Infant Statistics Definitions

Infant mortality is defined as the number of deaths of children under one year of age per 1,000 live births.

Fetal deaths occur prior to delivery, at greater than 20 weeks gestation, and refer to infants weighing less than 400 grams.

Perinatal mortality refers to deaths beginning at the point of viability, 22 weeks gestation, until 7 days after birth.

Neonatal deaths are those from birth until 28 days of age.

Post neonatal deaths occur at 28 to 364 days of age.

Child mortality numbers refer to those deaths within the first five years of life. Low birth weight (LBW) refers to infants born at less than 2500 grams

Very low birth weight (VLBW) refers to those born at less than 1500 grams.

APPENDIX G

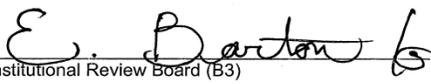
WAYNE STATE
UNIVERSITY

HUMAN INVESTIGATION COMMITTEE
101 East Alexandrine Building
Detroit, Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
<http://hic.wayne.edu>



NOTICE OF EXPEDITED APPROVAL

To: Gwendolyn Norman
Obstetrics/Gynecology
Hutzel Hospital

From: Ellen Barton, Ph.D. 
Chairperson, Behavioral Institutional Review Board (B3)

Date: July 30, 2009

RE: HIC #: 073209B3E
Protocol Title: Prematurity and Perceptions of Risk in the African American Family
Sponsor:
Protocol #: 0907007301

Expiration Date: July 29, 2010

Risk Level / Category: Research not involving greater than minimal risk

The above-referenced protocol and items listed below (if applicable) were **APPROVED** following *Expedited Review* (Category 7*) by the Chairperson/designee for the Wayne State University Behavioral Institutional Review Board (B3) for the period of 07/30/2009 through 07/29/2010. This approval does not replace any departmental or other approvals that may be required.

- Family Member Consent Form (dated 6/19/09)
 - Pregnant Woman Consent Form with HIPAA Authorization (revised 7/29/09)
 - HIPAA Summary Form (revised version received on 7/30/09)
-

- Federal regulations require that all research be reviewed at least annually. You may receive a "Continuation Renewal Reminder" approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval **before** the expiration date. Data collected during a period of lapsed approval is unapproved research and can **never** be reported or published as research data.
- All changes or amendments to the above-referenced protocol require review and approval by the HIC **BEFORE** implementation.
- Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the HIC Policy (<http://www.hic.wayne.edu/hicpol.html>).

NOTE:

1. Upon notification of an impending regulatory site visit, hold notification, and/or external audit the HIC office must be contacted immediately.
2. Forms should be downloaded from the HIC website at **each** use.

*Based on the Expedited Review List, revised November 1998

APPENDIX H

WAYNE STATE
UNIVERSITY

IRB Administration Office
87 East Canfield, Second Floor
Detroit, Michigan 48201
Phone: (313) 577-1628
FAX: (313) 993-7122
<http://irb.wayne.edu>

NOTICE OF EXPEDITED CONTINUATION APPROVAL

FILE

To: Gwendolyn Norman
Obstetrics/Gynecology
4501 Woodward Suite 101

From: Dr. Scott Millis *S. Millis*
Chairperson, Behavioral Institutional Review Board (B3) *SC*

Date: June 20, 2012

RE: IRB #: 073209B3E
Protocol Title: Prematurity and Perceptions of Risk in the African American Family
Funding Source:
Protocol #: 0907007301

Expiration Date: June 19, 2013

Risk Level / Category: Research not involving greater than minimal risk

Continuation for the above-referenced protocol and items listed below (if applicable) were APPROVED following Expedited Review by the Chairperson/Designee of the Wayne State University Institutional Review Board (B3) for the period of 06/20/2012 through 06/19/2013. This approval does not replace any departmental or other approvals that may be required.

- Research Informed Consent for Pregnant Patient with HIPAA Authorization (dated 7/19/2009)
- Research Informed Consent for Family Member (dated 6/19/2009)
- Research Informed Consent for Provider (dated 8/2/2010)

- * Federal regulations require that all research be reviewed at least annually. You may receive a "Continuation Renewal Reminder" approximately two months prior to the expiration date; however, it is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date. Data collected during a period of lapsed approval is unapproved research and can never be reported or published as research data.
- * All changes or amendments to the above-referenced protocol require review and approval by the IRB BEFORE implementation.
- * Adverse Reactions/Unexpected Events (AR/UE) must be submitted on the appropriate form within the timeframe specified in the IRB Administration Office Policy (http://www.irb.wayne.edu/policies/human_research.php).

NOTE:

1. Upon notification of an impending regulatory site visit, hold notification, and/or external audit the IRB Administration Office must be contacted immediately.
2. Forms should be downloaded from the IRB website at each use.

*Based on the Expedited Review List, revised November 1998

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ABSTRACT**PRETERM BIRTH AND PERCEPTIONS OF RISK
AMONG AFRICAN AMERICANS**

by

GWENDOLYN S. NORMAN**December 2012****Advisor:** Dr. Andrea Sankar**Major:** Anthropology**Degree:** Doctor of Philosophy

Background: African American women deliver preterm at a rate that is two to three times that of their white counterparts, and after decades of research, this disparity in birth outcomes still remains unexplained. While factors including income, education, neighborhood conditions, infection and stress have all been associated with prematurity, no combination of these factors has explained why the disparity persists. Recently, however, racism-specific stress has emerged as a possible factor contributing to this disparity. This study was designed to learn how preterm birth was explained by African Americans directly impacted by prematurity. **Methods:** Interviews were conducted with African American women with a history of preterm birth hospitalized for complications with their current pregnancy; the mothers of these women; the fathers of their unborn children; and African American physicians, nurses and medical assistants. A total of 25 recorded interviews were transcribed and analyzed for risk perception, and for explanatory models of risk. **Results:** With one exception, racism, racism-specific stress and the structural inequalities that impact the incidence of preterm birth for African American families were not acknowledged. All respondents shared a perception that the

pregnant woman's behavior was the primary explanation for her continuing experience with prematurity. The informants also agreed that stress and lack of support were strongly implicated in preterm birth. There were, however, differences between the groups. Notably, the competing priorities women faced in their roles as mothers, wives and homemakers, and their moral hierarchies for deciding how to fulfill these cultural roles, were often not recognized by providers. The emphasis by health care providers on gestational age at delivery often obscured the other important concerns that families faced. Additionally, this study found that patients and providers assigned significantly different meanings to "risk" and "harm," and that these differences impacted health behaviors. Conclusions from this study offer a direction for constructing culturally appropriate interventions, including the co-negotiation of risk, and inform best practices for the health care community.

AUTOBIOGRAPHICAL STATEMENT

I am a native Detroiter and I attended Detroit Public Schools. I received my Bachelor of Science in Nursing degree from the University of Michigan in 1974, and a Master's of Public Health degree from U. of M. in 1976. For the next three years I worked with for the Parent Child Development Center, a research and demonstration project to help low-income mothers raise healthy, bright children. In 1979 I began as staff nurse in Labor and Delivery at Hutzel Women's Hospital and in 1983 took the position of Perinatal Research Nurse Coordinator.

From 1991 to 2008 I was the research coordinator for the Maternal Fetal Medicine Unit network of the National Institute of Child Health and Human Development at Wayne State University. During that time I was involved in many aspects of the design and implementation of more than 30 randomized in-patient and outpatient clinical trials, cohort studies and registries. In 2002 I received a Nightingale award in the category of Research and Education for Michigan.

Early in my professional career I worked with the Visiting Nurse Association, and later conducted home health care for women with high risk pregnancies with Healthdyne/Matria Perinatal Services. I have taught undergraduate and graduate nursing students at the University of Phoenix and was a guest lecturer on Reproductive Disparities at Wayne State University.

I am currently employed at Wayne State University in the Department of Obstetrics and Gynecology as the Obstetrics Coordinator for the National Children's Study (NCS). This longitudinal study is designed to investigate, over a twenty-one year period, how all aspects of the environment impact the health and well being of children.