

6-2010

Experiences with Infant Mortality as Reported by Middle Class Black Women in Their Own Words

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**Experiences with Infant Mortality as Reported by Middle Class Black
American Women: In Their Own Words**

by

Lisa Paisley-Cleveland

A dissertation submitted to the Graduate Faculty in Social Welfare, in
partial fulfillment of requirements for the degree of Doctor of Philosophy,
The City University of New York
2010

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This manuscript has been read and accepted for the
Graduate Faculty in Social Welfare in satisfaction of the
Dissertation requirement for the degree of Doctor of Philosophy

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Abstract

Experiences with Infant Mortality as Reported by Middle Class Black
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Lisa Paisley-Cleveland

Advisor: Professor Miriam Abramovitz

The issue of Black Infant Mortality (BIM) appears to mirror the findings of disparities in poor health care and poor medical outcomes for minorities in the United States. The BIM rate of (13.3) is almost twice for all women (6.7) and more than twice the rate for white women (5.6). The BIM disparity holds even when variables such as income, education, and marital status are similar. This study explored the lived experience of infant loss through in-depth interviews with eight black-American middle-class women. It aimed to understand the contributing factors present among middle class black women, which could help in understanding the adverse birth outcomes for the target group studied.

All of the women revealed experiences with stress, from the time of pre-conception and throughout the entire pregnancy, although they gave little recognition to the negative affects of such stress on their medical health or the health of their unborn fetus. Coping mechanisms linked to a racial history, influenced the concept of self-expectation and responses to stress.

The presence of medical markers, a prominent theme, should be useful in the prevention of adverse pregnancy outcomes, if addressed. The role of race was implicated in quality of care issues, imbedded in medical views influenced by the prevalence of adverse birth outcomes for black women. The lack of timely medical tests to rule out the presence of a medical diagnosis was a probable consequence of such views.

In this study, an unexpected finding was that the majority of the fathers had a family history of premature births and infant loss.

Preface

My research journey deliberately lacked a specific focus in the beginning, but my personal experience helped to fuel my passion on the subject of Black Infant Mortality (BIM). Like most of the women in this study, I had no knowledge that my chances of giving birth to a premature baby were more than twice the rate of my white counterpart. My thoughts at the time of giving birth to our very premature baby girl was “what had I done wrong,” and on my better days this question gave way to an acceptance that “sometimes bad things just happen.”

Let me be clear, we were among the lucky ones; our baby girl who came three months too early survived. However, our baby experienced neonatal interventions at a specialty hospital for three months, and we watched and shared tears with parents as they said their final good-byes to their infants. With the calls in the middle of the night warning us of complications and uncertainties if she would survive through the morning, we understood how close we came to sharing the same fate – the death of our baby girl.

This experience provided the seeds for this project long before I took personal ownership of the topic as my research focus. There were the haunting questions about what went wrong, which fueled my interest, especially since I did all of the things they recommend a pregnant

woman should do. I entered pre-natal care during my first trimester; I was thirty-seven at the time, and this was my second pregnancy. I kept all my prenatal medical appointments, I took my vitamins, I ate healthy foods, and I followed my doctor's advice. I was happily married, we were living comfortably, and we were both solid wage earners. Nevertheless, when I reflect back on my pregnancy story, in its entirety, two things are troubling. One, I was under a great deal of job-related stress, which I did not give importance to at the time; I was handling it. I had no choice; my family needed two wage earners. I did not give the stress it was causing value, as I understood prior to becoming pregnant that I had no options in relation to discontinuing work. I continued with a "business as usual" attitude as did all of the women in this study, although this attitude I was projecting did not match how I was feeling.

The other troubling reflection of my own pregnancy story was a conversation I had with my doctor shortly after returning from a visit with my Mom in Florida. My Mom, who held various positions at a hospital for all of her adult life, urged me to see my doctor immediately upon my return home. "You are carrying very low for this period in your pregnancy. Make sure your doctor gives you an internal examination," she warned. It seemed as though my doctor responded with all of the breath of knowledgeable assurance she could muster and stated, "You are carrying low because your muscles are more relaxed from your previous pregnancy," almost (three years prior). "You are

carrying low,” were the exact words shared by a woman used by her doctor. She was placed on restricted activity. In my case, it was clear that there was no room for questions. I accepted this explanation intellectually; she (the doctor) was the expert. However, I had this nagging feeling that there was something wrong. In fact, I have to admit that I felt throughout the pregnancy that there was something “not right” (another common theme that emerged in this study). I could not describe it, other than that. I gave birth two days after that doctor’s visit. Our daughter arrived almost three months too soon and too small. She weighed 2lbs. and 5 oz. and slipped down to a mere 2 lbs. shortly after her birth.

I embarked on this study remembering the trail of tears left by all those women and the families I encountered at the time of the birth of my daughter, wanting to attach a voice and a person to the suffering experienced by so many. As I listened to the pregnancy story shared by each of the woman in this study, I was awed by their graciousness and strength in allowing me, for a short period, to enter into very private territory. It is my hope, that I was a good listener and that I will present their stories, in their voices, in a manner that honors their loss, and gives rise to new knowledge in understanding this stubborn phenomenon-BIM.

It was my Committee Chair, Mimi, who encouraged me to stick with this research. It has been a very long and tedious but rewarding journey.

I am so grateful to her for her faith in me and her support throughout this project.

I am so appreciative of my husband, Carles Cleveland, for enduring my absence, and knowing just what to say and when to say it. I thank my mother, who although has difficulty remembering the day of the week, her calls of encouragement were music to my ears. I must thank my two sisters who did just enough probing to let me know that they were interested in my work and its completion. Finally, to my children, thank you Jonas for being my role model, a great listener and a source of support. Jewelán, I thank you for surviving against the odds, and being the inspiration for this project.

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CHAPTER ONE

INTRODUCTION

“Something about growing up as a Black-American female in the United States that is not good for her childbearing health”

Dr. David, Neonatal Specialist and Researcher, 2009

Infant Mortality (IM) refers to the number of babies who die before their first birthday. Low Birth Weight (LBW) is the single most important predictor for infant survival for those infants being born too soon and too small (Hamilton, Arialdi, et. al., 2007). Infant mortality rates refer to the rate of infant deaths per 1,000 live births. Black infant mortality (BIM) refers to the rate of black babies who die before their fist birthday. According to the Health, United States, 2009 report (2010), the most current data demonstrates that in 2006, black newborns were more than twice (13.3) as likely as white newborns (5.6) to die within the first year of birth (CDC, 2010), and in some states the disparity widens to almost three times between black and white IM rates. However, until recently, the major hypothesis of most of the research was that socioeconomic factors, lack of access to care, and risk behaviors, were the most significant variables related to LBW and BIM. The more recent research findings reveal a more perplexing picture. What we now understand is that even when variables such as access to health care, income,

education, maternal age, and marital status are held constant, black women still deliver babies who die before age one twice as frequently as white women (Williams, 2000; IOM, 2003, Harrell; 2003 Mathews and Mac Dorman, 2008; Goza, 2008,). In fact, as reported in a NPR documentary on the black and white infant disparity (2008) concluded that a college educated Black-American women will have a worse pregnancy outcome than her white counter-part without a high school education. These facts required significant adjustment in thinking in relation to BIM and helped to shape the purpose of this qualitative study. The research question guiding this project is, *given the disparity in the infant mortality rates among middle class black and white women, are there factors attached to the pregnancy experience of middle class black women, which could help in understanding the adverse birth outcomes for this target group?*

This qualitative study targets a specific sample, which, with all things being equal, should not experience mortality rates at more than twice that of their white counterpart. It eliminates variables associated with teen-age pregnancies and the poverty paradigm in viewing the BIM phenomena, and instead focused on black, middle –class, professional, educated, married women between the ages of 25-40, with the intent of explicating material to gain a better understanding of those factors contributing to adverse birth outcomes for this target group.

There is little qualitative research, which focuses on the black woman's entire pregnancy story, and no research found which targets middle-class, married women who have lived through the experience of infant loss. The woman's reflective *pregnancy story*, captured in her own words, is missing from the research. This study captures the women's pregnancy story from the beginning to the end, by placing her at the center of the inquiry. The reviewed research produced areas of exploration for this research, which included emerging theories, offering newer explanations for the persistent disparity. However, little is known as to why the high BIM rates exist for black middle-class, educated, married women, and therefore this research study is exploratory in nature.

This is the study of eight black women, who experienced infant loss, and shared their very personal pregnancy stories. Through the shared lived experiences of infant loss, the study addressed the following areas:

MEANING OF PREGNANCY: Recollection of the woman's reasons for wanting to become pregnant (her decision), was the pregnancy planned vs. unplanned (wanted vs. unwanted), what key events occurred during this time frame, what kind of support system did she have, along with an integration of the woman's feelings and attitudes during these important preplanning and discovery stages of pregnancy.

FACTORS ASSOCIATED WITH MEDICAL CARE IN THE PREGNANCY EXPERIENCE: As health and medical issues became the

center of concern in caring for self and the well-being of her unborn infant, what were the factors or issues imbedded in the black middle-class female experience, related to health issues and medical interventions?

THE EXPERIENCES AND SOURCES OF STRESS DURING

PREGNANCY: The recollection of the existence of certain kinds of stress, the sources of stress and the coping mechanisms employed.

Additionally, a racial/historical context revealed and discussed.

REFLECTIONS ON LOSS: The women's account of the event (loss) and her thoughts on why the loss occurred to explicate any events, feelings, thoughts that would help to understand the poor birth outcomes for the women studied in this project.

Outline of Chapters:

Chapter two begins with a historical framework, which situates BIM and efforts to address the problem in a larger political/sociological context, followed by a comprehensive literature review. Chapter three provides an overview of the steps taken to carry out this research and describes the methodology used. Chapters four, five, six and seven present findings, which coincide with the above areas discussed. Chapter eight discusses and scrutinizes the findings and presents implications for Social Work practice.

CHAPTER TWO

REVIEW OF RELATED LITERATURE AND RESEARCH

Introduction: Historical Perspective

Throughout history, the explanations for infant mortality (IM) in general have shifted from environmental to social/political then to medical theories. The corresponding theories provide explanations about the kind of interventions and the resulting outcomes. For example, in the early 1900s factors linked to unsanitary conditions provided the explanation for the high rate of infant deaths. An estimated 124 of 1,000 babies born alive in 1910 died before their first birthday. The dire poverty of almost nine million immigrants, who arrived in the United States between 1900 and 1910 played a role as most were unskilled, illiterate, and without money. They lived in crowded urban areas, run down tenements, and in unclean conditions (Combs-Orme, 1998).

The 1912 act creating the Children's Bureau authorized it to investigate and report on all matters relating to children and identified infant mortality as its first priority. The Bureau's first major investigations looked into the causes of infant and maternal mortality. It found that infant deaths were often caused by unclean conditions, contaminated milk and water, and by the lack of adequate health care. It also pointed to low income, immigration status, poor crowded housing,

maternal ignorance, language barriers, and maternal employment, as the most important factors related to infant mortality. At the Presidential Address in 1913, before the American Association for the Study and Prevention of Infant Mortality, Emmett Holt, M.D, Professor of Diseases of Children, cautioned against taking the mother away from her infant after the first month of life to work long hours for little pay in unsanitary factories. He added that depriving the child of maternal nursing, and substituting a young, ignorant, inexperienced person, whose own disabilities made them ineligible for employment, was the single most harmful factor to infant life. Poor housing and low income also played a role. In homes without running water, infant deaths were 40 percent higher than in homes with water. As the father's income fell by half, infant mortality doubled. In 1918, the Children's Bureau ranked the USA seventeenth in maternal mortality and eleventh in infant mortality compared to other industrial nations.

The first practical effort to reduce IM took place when Julia Lathrop, Bureau Chief, embarked on ambitious educational programs for mothers (Combs-Orme, 1988). The programs included public education with specific emphasis on the benefits of breast-feeding, professional awareness and the establishment of milk stations in several cities for the distribution of milk (Combs-Orme, 1988). In 1921, Congress passed the Sheppard-Towner Maternity and Infancy Protection Act that provided federal funding for the health and welfare of women and children

administered by Children's Bureau. The Sheppard-Towner Act authorized the federal government for the first time to respond directly to the needs of women and children. Feminist activists and other reformers worked to get the statute adopted, as it was consistent with the social goals of the women's movement of the nineteenth century. The program of the short-lived Sheppard-Towner Act, made 183,252 "well baby visits," 3,131,966 home visits, and disseminated 22,020,489 pieces of literature. In its last 4 years, it served 4 million babies and 700,000 expectant mothers (Combs-Orme, 1988). Opponents of government supported health care including the American Medical Association, Catholic Church, and Public Health Service labeled the program as radical and worked to have it replaced. Funding for the Sheppard Act ended in 1929. Efforts to achieve further federal support of such programs did not succeed until the New Deal. However, due to the Sheppard-Towner programs Infant Mortality fell from 124 per 1000 live births in 1910 to 64.6 per 1,000 live births in the late 1930s (Combs-Orme, 1988).

Attitudes toward government programs changed after the 1929 Stock Market Crash and the ensuing Great Depression. Between 1932 and 1939, some 40 million people from all classes and races fell into poverty. The resulting New Deal programs included the 1935 Social Security Act widely viewed as the birth of the modern welfare state because it established federal responsibility for social welfare. The

Social Security Act included Aid to Families with Dependent Children (AFDC) (Title IV), that provided cash assistance to children in single parent households, mostly headed by women, and a program to improve Maternal and Child Health. This follow-up to the Sheppard Towner Act, set out to provide mothers and children, in particular those with low income or with limited availability to health services, access to maternal and child health services. The next important legislation for the health of children was the Emergency Maternal and Infant Care (EMIC) enacted by Congress in 1943 to address the needs of servicemen's wives and children during and after War World II. EMIC provided free prenatal, hospital delivery, postnatal, and pediatric care to wives and infants of noncommissioned service members (Combs-Orme, 1988).

Interestingly, Combs-Orme notes that in the 1950s, following the significant reduction of IM rate, social work and other professional groups lost interest in the problem, as measured by the number of professional presentations at National Conferences. Despite the persistence of the IM problem, Social Work's interest nearly disappeared by the 1950s due in part to the nation's preoccupation with the WW II and Social Work's increased interest in professional specialization and psychotherapy (Julia, 1992).

It is important to note that during the 1920s social workers attending a national conference expressed concern about excessive black infant mortality (BIM). This points to early recognition of the disparity

between black and white infant mortality rates, although it did not elevate to the level of a social problem (Combs-Orme, 1988).

Despite the lack of attention, white IM rates fell from 26.8 per 1,000 live births in 1950, to 23.6 in 1955, and 22.9 in 1960. For the same years non-white races stood higher at 44.5, 42.8 and 43.2 per 1,000 live births. The periods noted in Combs-Orme's (1988) historical account also coincides with some of America's important historical events, which adds contextual layering to the important changes in the response or lack of response in relation to BIM. For example, from 1932- 1939 America engulfed by economic devastation for several years as the Great Depression overwhelmed some 40 million people. The impact of this grave deprivation on the health of children eventually yielded various laws for needy parents and their children. From 1939-1945 America became preoccupied with fighting WWII. This period coincides with the significant drop in interest in relation to IM cited by Combs-Orme (1988). By the 1940's and 1950's the social work profession had turned its attention to the "psychological roots" reflecting its growing preoccupation with psychotherapy and specialization as a way to gain more professional autonomy and status (Julia, 1992). The resulting focus, on the psychological state of the mother, or as in the case of unwed mothers "no personality structure" (Solinger, 1993) shaped public and professional views and attitudes and served to justify punitive policies in the 1950s and early 1960s. In this historical context, the IM

disparity was slow to emerge as a social problem requiring redress.

In the 1960's IM became firmly situated in the medical domain. However, a new interest in providing early *prenatal care* to prevent *low-birth weight* focused on the prevention of birth defects; a cause championed by a popular president-John F .Kennedy (Combes-Orne, 1988). Congress amended Title V of the Social Security Act to provide funds for prenatal care to reduce IM and mental retardation, and to help disabled children. Congress also expanded the Medicaid (enacted in 1965) with the *Early and Periodic Screening, Diagnosis and Treatment (EPSDT)* program.

Between 1960 and 1980, little attention focused on IM except for a program, which linked birth certificates with death certificate records (Randall, 1990). The Centers for Disease Control and other U.S. Public Service Health agencies began to study infant deaths in relation to birth weight, type of delivery, and mother's race (Randall, 1990). The resulting National Infant Mortality Surveillance study (Randall, 1990) accumulated and analyzed data with a significant focus on birth weight, from a medical standpoint. The study revealed a 53% decline in IM rates from 1960-1980 among single-delivery infants, and found that birth weight was the strongest single variable in IM.

Important advances in neo-natal technology, medicine, and treatment for premature and LBW babies contributed to lower infant mortality rates (Shiono & Brahman., 1995). However, the racial disparity in IM

rates persisted. According to the Annual Vital Statistics Report (2008), for LBW black babies (less than 2500g); the IM rate for blacks was 13.9, compared to 7.3 for whites of the same weight. This suggests that black infants benefited far less than white infants did from advances and interventions in neonatal medicine. The question is why; is this issue of access to care, quality of care for specific groups, or other factors?

In seeking answers researchers considered the role played by black-white demographic and socioeconomic differences, along with other factors such as access to prenatal care, insurance coverage, variation in health-risk behaviors, beliefs, preferences, distrust of physicians, etc. (Laveist, 1993; Smedley, et al.,2003; Berg, 2001; IOM report, 2003; Goza, 2008).

Conclusion

The historical literature discussed in the preceding paragraphs informs us that government played a significant role in addressing IM during key times through the funding and introduction of important programs to assist vulnerable children and their mothers, which included valuable services to address IM. The decrease in the horrific numbers of infant deaths, especially from 1910 (IM rate of 124 per 1,000 live births) to 1930 (IM rate 64 per 1,000 live births) is directly attributable to government funded programs and services, and the work of the Social Work profession. The persistence of the high death rate of infant deaths,

and the various medical problems caused by preterm births, eventually placed IMR in general, back on the public agenda with research focused on medical and socioeconomic causes. However, the issue of BIM was slow to receive the status of *social problem* although “competent observers” were aware of its existence (Fuller & Myers, 1942). The BIM issue ignored and devalued for sometime, lacked the articulation and pressure for redress by those affected from the “inside” who did not understand it to be a problem but rather a personal tragedy.

The section below discusses the research focus, findings and assertions as the medical and social science communities attempt to understand the continued persistent disparity between white and black infant mortality rates.

Literature Review

Literature was reviewed in the following areas in preparation for this research project on Black Infant Mortality (BIM), which reflects past theories and current leading concepts and theories: *Major Past Research Trends and Problem Focus*: 1) Prevalence of premature and low birth weight (LBW) and its link to Black Infant Mortality (BIM); 2. Maternal socioeconomic factors affecting LBW and BIM; 3) Maternal Behaviors and BIM (risk factors); 4) The role of prenatal care on LBW and BIM; and 5) Patient/physician communication.

Major Current Research Trends:

6) Institutional racism and health disparities; 7) measuring stress and maternal health consequences; 8) Race, gender and stress, Implications for BIM and subsequent pregnancies; and 9) Relevance of a racial/history.

Premature births and low birth weight (LBW)

Babies born too soon (less than 37 weeks gestation) and too small (less than 2,500 grams) are the most important variables in infant mortality (Behrman & Butler, 2007). The prevalence of preterm birth in the United States constitutes a public health problem, but unlike many health problems, the rate of preterm birth has increased in the last decade. Since 1981, the rate has risen more than 30 percent (from 9.4%) (Behrman & Butler, 2007). There are significant, persistent, racial, ethnic, and socioeconomic disparities in the rates of preterm birth, which are naturally consistent with the disparities in the overall IM rates. The highest rates are for preterm births for non-Hispanic African Americans, and the lowest are for Asians or Pacific Islanders. The overall preterm birth rate was 12.8 in 2006. For the same period the preterm birth rate for blacks was 18.5 and for whites 11.7 (CD, 2009).

Great strides in treating infants born premature and in improving survival have occurred, but according to the Institute of Medicine Report (2006), little is known about how preterm birth can be prevented. If any

significant gains are going to occur in this area, it will have to focus on preventing its occurrence (Behrman & Butler, 2007).

According to the National Infant Mortality Surveillance Report (2007), the strongest predictor of black infant mortality (BIM) is low birth weight (LBW) (less than 2500 grams, less than 5 lbs, 8 oz.). LBW infants are 5 to 10 times more likely to die within the first year of life (Behrman and Butler, 2007). Several studies have sought to understand the causes of LBW and the racial disparity between white and black LBW rates by linking LBW to other variables. For example in 1994 the Center for Disease Control analyzed the link between LBW and period of gestation using data derived from birth certificates for live-born United States infants during 1981-1991. Forty-nine states and the District of Columbia reported data from 1981 through 1984, and all states from 1985-1991. The report found a higher incidence of short gestation periods (babies born too soon) in LBW black babies.

Another strong predictor of LBW is the LBW of a preceding birth. Racial disparities exist in this category as well. A black woman with a previous LBW delivery is almost four times more likely to give birth to another LBW infant, than a woman who had no history of LBW infant births (DiNitto, 1991; Rowley, 1994).¹ For White women, the probability is much lower than for black women. (Walker & Wallace, 1998).

¹ It is interesting to note that the literature contains very little information on preterm births or adverse birth outcomes linked to fathers' family history (Varner, 2005).

Unintended (unplanned) Pregnancies and Low Birth Weight

When unintended pregnancies are linked to LBW, primary determinant for black infant loss, the decreased access to abortion services appears to be the single most important factor (Gold, 1990; Randall, 1990). Almost half of the pregnancies in the United States are unintended (Finer & Henshaw, 2006). From 1972 to 1980, the national abortion rate rose annually due in large part due to the legalization of the procedure in 1973 by the Roe vs. Wade Supreme Court decision (Gold, 1990). The abortion rate stabilized from 1981 to 1992 and then began to fall, reaching its lowest rates in 1996 due in part to successful efforts to restrict access to abortions by increased intimidation tactics, and attacks on doctors performing abortions, in addition to an overall change in the political climate. It reached its second lowest rate in 2005 demonstrating a continuous decline. In 2005, 1.21 million legal abortions were performed, down from 1.3 million in 2000. As abortion rates fell, the LBW rate for infants increased. Between 1980 and 2000, the percentage of LBW infants increased by 11.8% suggesting a positive link between access to abortion services for women with unintended pregnancies, and the higher rate of LBW infants (Tomashek, 2002). In 2005 and 2006, the LBW for all races was 8.6% and 8.8% (respectively). For whites, 7.6% and 7.8%, and for blacks 14.1% and 14.7% (respectively), for women over the age of 20 (CDC, 2010). This is an

important trend to watch in line with abortion trends. The rate of unintended pregnancies affects the rate of LBW births, which is the strongest variable in adverse birth outcomes for black infants (Behrman & Butler, 2007).

Maternal Socio-Economic Factors Affecting LBW and BIM

In 1994, when the New Jersey BIM rates was 16.3 the New Jersey Department of Health and Senior Services and representatives from the Northern New Jersey Maternal/Child Health Consortium created a task force to study maternal and child care issues. After an extensive review of the research, the panel concluded that: *Improvements in socioeconomic status do not protect black infants against mortality and low birth weight as much as it does for white infants. In the United States even when variables such as income, education, maternal age, and marital status are similar, black women still deliver babies who die at twice the rate as white women* (New Jersey Blue Ribbon Panel, 1997). The finding of the consortium continues to receive corroboration from a substantial amount of recent research (Williams, 2000; Sable, 2000; Schultz, 2001; Goza, 2005; Zaslavsky, 2005; Collins, 2008).

Education

The results of one study demonstrated support for the Consortium's findings. It looked at the link between maternal education and infant

mortality rates among black and white women (Steinbrook, 1992). The researcher found that babies with normal birth rates had an equal chance of surviving in each group, regardless of mother's education. However, among LBW babies, the white IM rate (4.3 per 1,000 live births) was more than 2 times lower than the BIM rate (11.3 per 1,000 births) regardless of maternal education. Schoendorf's (1992) study of maternal education and IM rates found similar patterns. The study looked at national birth rates of 865,128 college educated white females and 43,230 college educated black females from 1983 –1985 and compared their infant death rates. When the analysis included LBW (weighing 2500g. or less), the most significant factor in BIM was LBW, which was more than twice the LBW rate of white infants. When birth weights were not factored into the IM rates of white and black babies born to college-educated, mothers were the same.

Other studies linked mother's level of education and the rate of infant mortality, without factoring in the weight of the infant. For example, the more recent data provided by the National Vital Statistics Report, 2006, reveal infant mortality rates generally decrease with increasing education of the mother, for black and white infants, but with little consequence on the size of the disparity between the two groups. The disparity in the rate of infant deaths between white and black mothers with more than 16 years of education is 63% (IM rate for whites 3.76 for blacks 10.21). The elimination of education as a factor results in

a disparity of 58% (IM rate white 5.72 compared to 13.50 for blacks) (National Vital Statistics Report, 2006). Clearly, the level of education is a mitigating factor, but the persistence of the significant disparity, in light of what most researchers theorized to be a mitigating variable is puzzling. In other words, a college educated Black-American women, will have a worse pregnancy outcome than her white counter-part without a high school education (Collins & David, 2009).

Marital Status

A woman's marital status is another important factor in LBW as it may be an indicator of the presence or absence of emotional, social, and financial support during a pregnancy (Sharma, 1998; Frye 2008). However, as with other demographic variables, marriage may afford some women more protection than others may. Although, marriage improved the rate of IM for whites and blacks by 17% and 14% respectively, the disparity between the two groups, once more, remained approximately the same (National Vital Statistics Report, 2006). Nevertheless, the degree to which a spouse is present and provides emotional support is a protective factor in preventing adverse pregnancy outcomes (Gaudino, 1999; Milligan, 2002, Pagnini & Reichman, 2000).

It is interesting that being unmarried does not have the level of influence on the overall BIM rate as one might expect (Sharma, 1998). Current statistics reveal that being unmarried increased the BIM rates by

4% for black women compared to 24% for their white counterparts (National Vital Statistics Report, 2006).

Maternal Behaviors and BIM (risk factors)

According to a large body of research, certain risk-behaviors are contributing factors to poor pregnancy outcomes. Such individual risk factors cannot fully explain population-level differences in IM rates but they are important to this review and discussion (Berger, et al., 2001; Link & Phelan, 1995; Rowley, 2001).

Cigarette Smoking/Consequences

There is a strong link between cigarette smoking and LBW (Moner, 2000). According to the Child Trend Data Bank (2007) 8.4% black women and 13.8% white women in 2004 reported smoking while pregnant. If these infants survive, they remain vulnerable to many complications, including respiratory, gastrointestinal, immune system, central nervous system, hearing, and vision problems. Longer-term problems may include cerebral palsy, mental retardation, visual and hearing impairments, behavior and social-emotional concerns, learning difficulties, and poor health and growth. Interventions which include counseling, multiple components, behavioral strategies, support, multiple contacts, and self-help manuals are effective in significantly

decreasing tobacco smoking in pregnant women (Gielen & Windsor, 1997; Moner, 2000; Misra, 2008).

Alcohol Consumption/Consequences

According to the Center of Disease Control (2006), drinking alcohol can harm a baby at any time during pregnancy. Prenatal exposure to alcohol can cause a range of disorders, known as fetal alcohol spectrum disorders (FASD). One of the most severe effects of drinking during pregnancy is fetal alcohol syndrome (FAS). FAS is one of the leading known preventable causes of mental retardation and birth defects. If a woman drinks alcohol during her pregnancy, her baby can be born with FAS, a lifelong condition that causes physical and mental disabilities. Abnormal facial features, growth deficiencies, and central nervous system (CNS) problems characterize FAS. People with FAS might have problems with learning, memory, attention span, communication, vision, hearing, or a combination of these. FAS is a permanent condition, and it affects every aspect of an individual's life and the lives of his or her family. Almost 1 in 12 pregnant women in the United States reports alcohol use (14.5 % white and 15.7 % black). About 1 in 30 pregnant women in the United States reports binge drinking (having five or more drinks at one time). FASD is 100% preventable if a woman does not drink alcohol while she is pregnant.

Drug Use/Consequences

According to the results from the National Survey on Drug Use: Substance Abuse: Mental Health Administration (2005), almost 4 percent of pregnant women (3.6 white and 6.2 black) use illicit drugs such as cocaine, Ecstasy and other amphetamines, with marijuana being the most prevalent. These, and other illicit drugs, pose various risks for pregnant women and their babies, such as LBW, preterm birth, withdrawal symptoms, or learning and behavioral problems, and birth defects.

Unsafe Sex/Consequences

Behaviors attached to pregnancy and unsafe sex practices are associated with BIM. For example, there is a relationship between women's ability to negotiate safer sex, to prevent Bacterial Vaginosis and other sexually transmitted diseases, found to increase the rate of pre-term labor (Hillier, et al., 1995). According to Guttmacher Institute (2008), 62 million U.S. women are in their childbearing years (15–44), 43 million women of reproductive age women, or 7 out of 10, are sexually active and do not desire to become pregnant. Sixty-four percent of reproductive-age women who practice contraception use reversible methods, such as oral contraceptives or condoms. The Center of Disease Control: Advance Data (2004) reports that condoms, the only method that protects women against Bacterial Vaginosis, and STDs, are used by 11% of the 64% reproductive- age women (ages15-44).

Hygienic Practices/Consequences

A hygienic practice, specifically vaginal douching, is implicated in the higher prevalence of Bacterial Vaginosis infections in African American women. Although, douching temporarily affects the vaginal ecology, the changes may last long enough to increase the risk of infection. In a national cross-sectional study of 4,665 women conducted as part of the National Survey of Family Growth (2003), vaginal douching was associated with a 30% higher risk of having a low birth weight infant. Approximately two thirds of African American women, and one third of white American women, douche regularly (at least 1x per month). However, also implicated in a higher incidence of Bacterial Vaginosis is stress (Giscombe, 2005).

Summary

Fewer black women than white women smoke while pregnant (8.4% and 13.8% respectively), and only 1% more black women drink while pregnant compared to white women. There is a 1% difference between pregnant black and white women using a form of contraception, which, protects against Bacterial Vaginosis. In total, the findings suggest that factors other than risky behaviors contribute to poor birth outcomes among black women. This is particularly important to note in a climate, which blames women for an ever-wider range of social problems. Gates-

Williams, et al., (1992) warns of a danger in emphasizing the personal responsibility of African-American pregnant women in a society where "high risk" is synonymous with being African American, and where the failure to meet the needs of women and children becomes a metaphor for poverty and despair.

Prenatal Care and BIM

There are two primary issues, addressed in research in relation to prenatal care: 1) utilization and 2) effectiveness. A significant amount of research focused on understanding why more women are not taking advantage of early prenatal services, while other more recent research is questioning the effectiveness of prenatal care on reducing LBW and BIM.

Utilization

The Institute of Medicine (1988), examined the utilization issue and presented 11 items identified as barriers by pregnant women to prenatal care: 1) Financial, 2) Transportation, 3) Little value assigned to prenatal care, and 4) Not aware of being pregnant. Others included: 5) Negative institutional practices, 6) Ambivalence/ fearful, 7) Limited provider availability, 8) Childcare, 9) Dissatisfaction with caregiver, 10) Other fears, and 11) Other reasons. It is interesting that almost half the list relates to the lack of alignment with the health care provider. This may

be attributable, in part, to issues, which this paper will address in the patient/physician communication section.

In another study, researchers examined the timing of prenatal care, the psychosocial issues related to its use, and individual characteristics of the women (Pagnini & Reichman, 2000). They found that between 1988 and 1996 only 37 % of the 90,000 women in a New Jersey Head Start program took advantage of prenatal care in the first trimester, compared to 78% of all women in the state. The State estimated that Head Start served almost 18% of all pregnant Medicaid recipients in 1988. Researchers also studied factors contributing to the timing of entry into prenatal care. They found that marriage and employment during the first trimester had a positive influence, those women in treatment for depression, and other mental health problems such as violence or abuse initiated their prenatal care earlier than women not in treatment did. Surprisingly, crisis such as eviction, homelessness, involvement with the justice system, had no impact on the timing of the initiation of care. However, living in poor housing reduced the likelihood of early care by 12%. The mother's desire for the pregnancy (wantedness) turned out to be the most significant factor in the timing of entry into prenatal care. Women with an unwanted pregnancy were 63% less likely to secure early prenatal care than those who wanted their infants (Pagnini & Reichman, 2000).

These findings supported by another study of mothers in Texas, which examined the rate of unintended childbearing, maternal beliefs and delay of prenatal care. The women who reported that they did not want to get pregnant were 57% more likely to delay seeking prenatal care (Mayer, 1997). Women with unwanted pregnancies were also the least likely to recognize that they were pregnant for the first six weeks (Kost, et al., 1998). Additionally, researchers found that women who wanted their babies had coexisting behaviors and attitudes consistent with promoting a positive birth outcome. For example, the women who intended to become pregnant were more likely to seek out early prenatal care. However, these same women are no more likely, when compared to women with comparable social and demographic characteristics, to follow a recommended schedule for prenatal visits, or to follow their clinician's advice on health related issues once they begin care (Kost, et al., 1998).

The utilization of prenatal care is linked to the availability and proximity of services to women in need. Distance, access to transportation, discontinuity of providers, poor communication, long waits for service, inconvenient schedules, health insurance issues and insufficient number of primary health care providers in deprived areas, are all factors linked to late entry into prenatal care (Pagnini & Reichman, 2000).

However, other studies suggest that the weight of access and provider availability may not be a strong variable in women's decision to secure prenatal care. Shi et al, (2004) tested the extent to which primary care physician supply (office based primary care physicians per 10,000 populations) moderated the association between social inequalities, infant mortality and low birth weight in the fifty states of the USA. The researchers found that increased supply of primary care practitioners, especially in areas with high levels of social disparities, did not impact infant mortality and low birth weight. This finding supports an emerging understanding that utilization issues and supply of primary care providers does not explain the persistent significant disparity between black and white infant mortality rates. Black -American women still suffer from the death of their infant at a rate that is 2X as high as white women even when they have access to care. La Veist (2002) suggests that the reason why large numbers of black women do not avail themselves to early and consistent pre-natal care may go beyond barriers to access. Other factors may include fear, distrust, past negative experiences with the health care system, mother's feelings about her pregnancy, and a low value placed on prenatal care, similar to the findings of the IOM report (1988) discussed above (p.25).

The Department of Health and Human Services' Healthy People Initiative, called for an increase to at least 90% the proportion for all pregnant women receiving prenatal care in their first trimester of

pregnancy by 2000. In 1997, 83% of pregnant women in the United States received prenatal care in their first trimester: 72%-74% for black and Hispanic women (respectively) (Pagnini & Reichman, 2000). In 2003, with 84.1% of pregnant women receiving early prenatal care, the standard was still unmet. One year later in 2004, 83.9% of pregnant women (41 states reporting) entered prenatal care in their first semester, 76.4% blacks and 85.4% whites. (CDC, 2007). The increasing trend in the number of pregnant women in prenatal treatment appeared to have stopped (83% in 1997, 84.1% in 2003 and 83.92% in 2004). It is unclear if the levels of prenatal care utilization are tied to the black and white infant mortality disparity.

Prenatal Care: Effectiveness

For the past fifteen years, researchers questioned the effectiveness of prenatal care in addressing the black and white IMR disparity. There is significant research demonstrating the effectiveness of prenatal care (Mason, 1991; Sharma, 1998), while other research findings demonstrate the lack of its ability to effect any change in the BIM rates, supported by the persistent disparity (Rowley, 1995; Goldenberg, 1998; Landis, 2006). There is a trend toward looking at specific types of medical issues and risk factors, with corresponding interventions in reducing BIM. For example, a high percentage of both symptomatic and asymptomatic urinary tract infections are associated with poor birth outcomes. Several

randomized trails have provided confirmation that treating the infections with antibiotics reduces the risk of preterm births (Goldenberg, 1998; Misra, 2008). The same results were found in treating Bacterial Vaginosis, especially among black women, who have significantly higher rates of Bacterial Vaginosis than other women (30 percent blacks vs.10 percent whites) (Misra, 2008). Another example is a model used by the Early Start (ES) program at Kaiser Permanente Northern California (KPNC) Prenatal Services. The KPNC is the largest HMO-based prenatal substance-abuse program in the United States, currently screening more than 39,000 women each year. KPNC implemented a fully integrated service delivery model with one-on-one counseling, which screens pregnant women at risk for alcohol, tobacco, or drug use. Such screening is part of the routine prenatal care package offered to all patients. Findings on women who were screened but did not accept assessment or treatment, compared to women who received early start treatment demonstrated: risk of stillbirth 16.2 higher, risk of placental abruption 6.8 times higher, risk of pre-term delivery 2.1 times higher, and risk for low birth weight (under 5.5 pounds) 1.8 times higher. Additionally, the risk of neonatal ventilation was 2.2 times higher. These results are promising especially if validated by an outside research source. On face value, the approach also appears highly replicable.

Such findings underscores the need for more targeted approaches on specific risk-factors, including women who are victims of domestic

violence, considered to be a potentially modifiable risk factor for LBW births (Neggers, et al., 2004; Talliac, 2007). According to the Family Violence Prevention Fund report (2008), women experiencing abuse in the year prior and during pregnancy were 40-60% more likely than non-abused pregnant woman to report a host of medical problems including vaginal bleeding, high blood pressure and urinary tract infection, and were 37 percent more likely to deliver underweight infants. The findings calls attention to the importance of screening pregnant women for abuse by an intimate partner, and the need for developing and implementing interventions to address physical and psychological abuse integrated in prenatal care service delivery.

There is no clear linear model of cause and effect in addressing the disparity in the black and white mortality rates. However, prenatal services, as carried out by the majority of providers, are not working to reduce the significant IMR disparity. This is especially disconcerting in light of the growing number of preterm births (Behrman & Butler, 2007). Therefore, efforts directed toward increasing early access to the current prenatal care systems may continue to yield poor results (Healy, et al., 2006).

Prenatal Care and Patient/Physician Communication

Any discussion on prenatal care must include the quality of the patient/physician communication, the main determinant in an effective

patient/physician relationship. According to much of the literature, the patient/doctor relationship plays a major role in the perpetuation of disparities in the delivery of healthcare services on individual and systemic levels (Johnson, 2004; Williams, 2000; LaVeist, et al., 2003; IOM, 2003). The disparities are persistent and are present across medical diagnosis.

It is difficult to address the issue of patient/physician communication without placing both parties in a healthcare framework, that suffers the ills of institutional racism, is extremely complicated, and by most accounts, in need of major reform. A problem from the outset is that the patient /physician communication exists within a context of competing forces, vulnerable patients with immediate and urgent medical needs, and physicians who must answer to outside authorities with requirements that often are in conflict with patients' needs (i.e. insurance companies, policies of the institution, etc.). Such forces, in addition to a myriad of other factors, challenge the quality of the communication from the beginning. Additionally, patients and providers coming together in a dialogue around health issues bring with them their personality issues, social and cultural perspectives, values, sexual orientation, beliefs etc. Within this layered complexity of issues, there is much to get through, including the medical issue(s) at hand. However, in the case of this particular professional interaction, the physician is the "expert" and needs to possess the skills that will allow him or her to transcend many

of these issues, and present a culturally sensitive communication style. Not only does such a style require a certain amount of dedicated training and commitment, but it also requires time. Nevertheless, the patient/physician communication is of particular importance as it relates to minorities who, according to the Bureau of Census (2000), are expected to comprise 40% of the United States population by 2035, and 47% by 2050. This fact should create some urgency in the medical profession to transform its practices to meet the needs of a more diverse population. The Institute of Medicine report Unequal Treatment (2003), recognizes that such changes must include a high value on communication skills, interpersonal sensitivity and cultural competence. Such changes also represent the single most important factor in closing the gap in healthcare disparities experienced by minorities (Johnson, 2004).

Quality of Communication with MD/Benefits, Consequences and Influences

The quality of the communication is extraordinarily important in the delivery of proper medical care to patients. Research demonstrates that communication improves patient outcomes across all medical practices. One review of randomized controlled trials on patient-physician communications reported that the quality of communication in the history-taking and medical management (discussing portions of the

treatment with patients) positively influenced patient outcomes in 16 of 21 studies (Travaline, 2005). Positive outcomes influenced by such communication include emotional health, symptom resolution, and pain control. It also reduced anxiety in patients whose physicians encouraged questions, and who encouraged their patients to share in the decision-making process (Travaline, 2005). In individual studies outcomes linked to effective communication skills, included adherence to therapy, understanding of treatment risks, and even contributed to reduced risk of medical mishaps and malpractice claims were evidenced (Travaline, 2005).

While the research is substantial about the cause and effect relationship between communication and quality healthcare, it also reveals a range of opportunities for missteps in communication to occur. The literature refers to many reasons for poor communication, which include, but not limited to, insufficient time for patient/physician interaction, racial biases and cultural incompetence (Cooper & Roter, 2003; Chin, et al. 2001), physicians training, and patient health literacy (Williams and Davis, et. al, 2002; Travaline, Ruchinskas, et al., 2005). The time issue, although a hot button for both patient and doctor, appears for the most part, to be outside the realm of control of either party. Outside forces heavily dictate the amount of time a physician spends with a patient. However, there are factors more attached to personal ideas and feelings held by the physician, such as negative

attitudes or assumptions made about a patient's personality, motivation or level of understanding that may influence the length of time of a physician/patient visit. Numerous studies suggest that patient's race and ethnicity influences physicians' beliefs about and expectations of patients (van Ryn & Burke, 2000). If time spent with a patient is short, there is little opportunity to change or adjust such feelings and beliefs. In understanding how race and ethnicity might affect the length of time spent with a patient, Cooper & Roter (2003), using pre-visit and post-visit surveys, and audiotape analysis, in 16 urban primary care practices studied 252 adult patients (142 African-American patients and 110 white patients) receiving care from 31 physicians (of whom 18 were African-American and 13 were white). Audiotape measures of patient-centeredness; patient ratings of physicians' participatory decision-making styles, and overall satisfaction were obtained. The findings revealed that the length of visits was shortest among white physicians with African American patients (13.2 minutes) and longest among African-American physicians seeing white patients (18.4 minutes). The average length of visit was generally longer among African-American physicians and African American patients by 2.15 minutes. Visits to African American patients were characterized by a higher level of physician's verbal dominance generally, but was highest among white physicians and African-American patients, and lowest among white patients and African-American doctors. Interestingly, patients in race-

concordant visits were more satisfied and rated their physicians as more participatory (involving patients in communication and decisions). Audiotape measures of patient-centered communication behaviors did not explain differences in participatory decision-making or satisfaction between race-concordant and race-discordant visits (Cooper & Roter, 2003). Therefore, researchers concluded that the association between race concordance and higher patient ratings of care is independent of patient-centered communication, suggesting that other factors, such as patient and physician attitudes, may mediate the relationship. One could conclude that patients' perceptions of the quality of communication were more influenced by race-concordance with doctor, rather than by the actual degree of patient participation. Cooper & Roter (2003) also found generally, African American, and other ethnic minority patients, report less involvement in medical decisions, less partnerships with physicians, and lower level of satisfaction with care, which is more reflective of the majority of doctor/patient visits, which are race-discordant.

Marshall and Janz (1990) suggest that physician's ineptness in communication, especially in the area of prevention, may explain why more women do not avail themselves to early prenatal care. These researchers examined the attitude toward prevention among 33 physicians and found that the overwhelming majority of physicians did not feel successful in helping their patients modify behavior around smoking, alcohol use, exercise, diet, drug use or stress. Therefore,

researches concluded, “*Black women who are seen early for prenatal care may face doctors who are ill prepared to hold substantive conversations around behavior or other health-related changes to ensure a positive birth outcome*” (Marshall & Janz, 1990). This fact underscored by the Family Violence Prevention Fund (2008), which reported that few doctors screen their patients for abuse even though 1 in 12 pregnant women are battered.

A study, conducted by Bennett and Switzer, et al (2006) adds strength to the Marshall & Janz findings. Researchers studied 202 African-American women involved in a prenatal care obstetric practice at the University of Pennsylvania, and examined the link between low literacy and poor medical adherence, in maternal care utilization. Although the individual items addressed a range of prenatal topics, including the assessment of well-being of the mother and baby, the inconveniences of prenatal care (long wait), patient-clinician communication (questions), and medical testing, communication with clinicians emerged as a central theme and organizing theme underlying the discussion of all of the items relating to obstacles to care. In addition, the quality of this communication was described as a motivator for, or an obstacle to prenatal care for women in every focus group. Effective communication, embodied the view of “breaking it down,” keeping it simple and engaging in back and forth communication was

described as encouraging, whereas ineffective communication discouraged use of care (Bennett, Switzer, et al., 2006).

There are many variables contained in effective patient/physician communication, which when skillfully done seamlessly incorporates all of the elements so far mentioned in this discussion. However, given the changing demographics mentioned above, Dr. Beverly Coleman's (2000) claim that a significant gap in doctors' response to the medical needs of his/her patients is often caused by what she terms "cultural disregard," may be especially useful. She describes "cultural disregard" as "not knowing what one does not know." There is quite a bit of literature that speaks to the value of "cultural competence," but it is important to define the concept before discussing its importance. Campina-Bacote (2003) defines cultural competence, at the patient-provider level as - "*a process in which the healthcare provider continuously strives to work effectively within the cultural context of a client who may be an individual, a family or community.*"

There is no lack of interest and little debate about the importance of cultural competence as a powerful, but often-missing factor in patient/physician communication. Poor integration of cultural competence in patient/physician communication can lead to serious misinterpretations (Travaline & Ruchinskas, et al, 2005). For example, the Surgeon General's Supplemental Report on Mental Health (1999) raises the concern that diagnostic assessments can be especially

challenging when a clinician from one ethnic or cultural group uses the DSM–IV Classification to evaluate an individual from a different ethnic or cultural group. Misinterpretations may occur when a clinician who is unfamiliar with the gradation of meanings in an individual’s cultural frame of reference, may incorrectly judge as psychopathology those normal nuances in behavior, beliefs, or experiences attached to the individual’s culture. For example, Asian patients are more likely to report their somatic symptoms, such as dizziness, while not reporting their emotional symptoms. However, when questioned further, they do acknowledge having emotional symptoms. The same is true in how patients from different cultures deal with and describe pain (Chin, et al., 2001). The aforementioned Surgeon General’s report, discusses the different meanings of an illnesses held by different groups, which may reflect firmly held attitudes and beliefs a culture embraces about whether an illness is “real” or “imagined,” or whether it is of the body or the mind. There may be some question as to whether the illness deserves sympathy, how much stigma surrounds it, what might cause it, and what type of person might succumb to it. It is extraordinarily important for the health provider to understand that cultural meanings of illness have real consequences. Such meanings can affect whether people are motivated to seek treatment, how they cope with their symptoms, how supportive their families and communities are, where they seek help (i.e. mental health specialist, primary care provider, clergy, and/or traditional

healer), the pathways they take to get services, and how well they fare in treatment. There were, and are, vivid and painful examples of this as we watched patients, families and communities deal with the HIV/AIDS epidemic.

Additionally, the literature suggests that cultural competence extends outside the interpersonal contact between patient/physician. It can be enhanced by: 1) Providing services and resources in the language of patients, 2) Use staff who share cultural background of patients, include family members, traditional healers, community health workers, etc., and 3) Situate services and programs in locations that are easily accessible to intended patients (IOM, 2003).

The traditional training of physicians foster a level of disconnect from patients as it values distance for the sake of objectivity and accuracy in forming a diagnosis (Travaline, 2005). Additionally, patient's health literacy plays a role as a critical factor affecting patient-physician communication and health outcomes. For example, not understanding prescription instructions, possessing insufficient health vocabulary to report symptoms accurately, and not knowing the meaning of medical terms (i.e. polyp, tumor, lesion, and blood in the stool), does affect treatment outcomes and patient's communication comfort level (Williams, 2002).

Efforts that are more recent objectively focus on evaluating patient/physician communication as a core competency in various

accreditation settings, including the Comprehensive Osteopathic Medical Licensing Examination, United States Medical Licensing Examination, and the American Board of Medical Specialties' certification (Traveline, 2005). Additionally, increasing diversity in the physician workforce will help to push for redress of issues discussed in the preceding paragraphs, especially if they are consistent with reforms to the healthcare system. The evidence of significant positive medical outcomes as a result of more participatory, culturally sensitive patient/physician communication, suggests that this is an area requiring heightened and immediate attention, is an important component in reducing the general healthcare disparities experienced by minorities across medical diagnoses, which includes BIM specifically (Johnson, R. 2004, Travaline, 2005, IOM 2003).

Institutional Racism and Health Disparities

The most important adjustment in thinking in relation to BIM is an emerging understanding that improvement in a mother's socioeconomic status does not protect black infants from mortality and low birth weights as much as it does white infants. What is evident, over the course of almost fifteen years, is emerging literature, which focuses on the overarching role of race as a differentiating factor on individual and institutional levels in understanding healthcare disparities. It is important to understand and accept the notion that institutional racism is

an unpleasant reality for all blacks across the socioeconomic spectrum with real health consequences attached (Gates-Williams, et al., 1992; Harrell, 2000; Williams & Rucker, 2002).

Link and Phelan's (1995) theory that some *social conditions* may be *fundamental causes* of disease provide another perspective in the examination of health disparities in general, and BIM specifically. The researchers define *social conditions* as factors involved in a person's relationship to other people. This includes relationships with spouse/partner, positions occupied within one's social and economic structures, in addition to factors such as race, gender, stressful life events, as well as stress-process variables like social support. *Fundamental causes* embody access to important resources, affect multiple disease outcomes through multiple mechanisms, and consequently maintain an association with the disease, even when intervening methods change. *Fundamental causes* require broad-based societal interventions that could result in substantial health benefits to diseased populations (Link & Phelan, 1995).

Racism, a social condition, the *fundamental cause* for the increase in diseases for blacks and other minorities, aligns with this theory. According to the Institute of Medicine Report (2003), although the overall health in the United States population has steadily improved, the evidence of health disparities across all medical diagnoses is significantly higher for racial and ethnic minorities than for whites. Such

disparities appear to reflect the presence of institutional racism, which has an insidious and historical presence in housing, employment, education, etc, and is well documented (Williams & Rucker, 2000; Smedley, et al., 2003; Zaslavsky & Ayanian, 2005).

Understanding racial disparities in health care requires recognition and appreciation of the ways in which racism has operated and continues to operate in society. It may be helpful to provide a definition of racism, as it pertains to institutions for context:

A system of dominance power, and privilege based on racial group designation; rooted in the historical oppression of a group defined or perceived by the dominate-group members as inferior, deviant, or undesirable; and occurring in circumstances where members of the dominate group create or accept their societal privilege by maintaining structures, ideologies, values, and behavior that have the intent or effect of leaving non-dominant-group members relatively excluded from power, esteem, status, and/or equal access to societal resources (Harrell, 2000).

It is interesting to note that only two years ago Congress issued an unprecedented apology to black Americans “for wrongs committed against them under slavery and Jim Crow segregation laws” (Abramas, 2008). Such laws and wrong doings have influenced and under girded attitudes and stereotypes that are difficult to change, and are reflected throughout our institutions. Congress’ action gives recognition to the

harm such laws have caused, a step forward in redressing this stubborn and complicated problem in America.

It is also interesting how some institutions have gone about addressing this sensitive and complex issue. For example, the year is 2005, a facilitator, a Black male of some notoriety, addressed a room full of black students; high achievers entering their first year on the Engineering track, at a University in the Northeast region. The University is one of the top 10 in the nation in Engineering, and this group of black students represented 10% of the incoming freshman class consisting of the 1,500 students from all over the world. Despite the fact that these students, for the most part, came from upper and middle class educated two parent households, the university understood that it needed to give these students some extra arsenal in dealing with a challenge that could potentially affect their educational success. Following an exercise, which resulted in all of the participants making a huge assumption, the facilitator made his point: “You will encounter some professors, students, administrators that will take one look at you and assume they know who you are.” He continued, “You cannot believe that because you are here, assumptions will not be made by others about you. They will first see the color of your skin before they know anything about you, and they will think they know who you are.”

This attempt to inoculate these students from what the university perceived as the inevitable racism they will encounter, reveals the stark

accepted reality by the University that race, or skin color, cannot be ignored. To do so would discount the reality of how segments of society are perceived, welcomed, and allowed full participation in this country's political and economic structure (La Veist, 1993). This approach seeks to warn the victim, in an attempt to manage expectations and responses, hoping to reduce the impact when racism is experienced, which could lead to poor academic outcomes. There is an expectation that racism will occur as people bring their prejudices and stereotypes into their work places.

The persistence of such stereotypes also evidenced in a national survey, which found that 56 percent of Caucasians believed that blacks prefer to live off welfare, 51 percent viewed blacks as unintelligent, and 44 percent viewed blacks as lazy. Comparatively, white persons believed that only 4 percent of whites prefer to live off welfare, 6 are unintelligent and 5 percent are lazy (Davis and Smith, 1990). On the other hand, one reason for the insidious nature of the problem could be that much of the behaviors are unconscious, and unintentional (Allen, 1995). Biases based on racial stereotypes often occur automatically, and without conscious awareness, even by a person who believes that they do not endorse racist beliefs. This is one reason for the inoculation approach (attempts to prepare the victim) since high levels of acceptance of such negative stereotypes, as in the aforementioned survey, are

resistant to change, and have real consequences across all major institutions (Williams & Rucker, 2000).

Biases based on racial stereotypes infiltrate institutions and the consequences related to health-care disparities are real. For example, another study found that physicians' abilities to detect the severity of pain did not differ for Hispanic versus non-Hispanic white patients, yet Hispanic patients were markedly less likely than non-Hispanic white patients to receive adequate analgesia (Todd, et al., 1994).

In relation to access to care, a significant amount of research is demonstrating that when equivalent level of care is accessed by blacks, racial and ethnic minorities still experience a lower quality in the health care services, across all medical services and procedures (Cromwell, McCall, et al. 2005; IOM, 2003). For example, researchers reviewed the use of coronary procedures and subsequent mortality rate over a span of 2.5 years for over 700,000 elderly patients hospitalized in 1997 for Ischemic Heart disease. Using the Medicare claims for patients making up the major racial and ethnic groups (African-Americans, American Indian, Hispanic and Asian patients), the findings revealed that these groups are much less likely to receive the benefits of revascularization procedures. These patients had substantially lower survival rates on average than white patients with the same Medicare insurance coverage and comparable access to hospitals performing these procedures (Cromwell, McCall, et al. 2005).

Another study, which supports the above findings, conducted by Van Ryn & Burke (2000), to understand the role of patients' race and socioeconomic status on physician's perceptions and level of care. Researchers surveyed 193 physicians to assess their perceptions of 842 patients (57% white and 43% African American) following post angiogram hospital visits. Physicians were asked to rate their patients on a variety of personal characteristics including self-control, education level, pleasantness, rationality, independence, and responsibility. In addition, physicians were asked to rate their feelings toward the patient and their perceptions of their patients' degree of social support, tendencies to exaggerate discomfort, likelihood of drug and alcoholic abuse, and other characteristics. Researchers assessed patients' fragility/sickness, depressive symptoms, social assertiveness, feelings of self-efficacy and perceived social support. These variables along with information on physicians' age, sex, race and medical specialty were entered into logistic regression analysis to control for the impact of these variables on physicians' assessment of patients. The results demonstrated that the patients' race and socioeconomic background do influence physicians' perception, even when controlling for differences in patients' socioeconomic status, personality attributes, degree of illness. African American patients were rated as less intelligent, less educated, more likely to abuse drugs and alcohol, more likely to fail to comply with medical advice, more likely to lack social support and less

likely to participate in cardiac rehabilitation. These findings demonstrate that physicians' diagnostic decisions are influenced by patient's race, regardless of socioeconomic status.

Other research, which focused specifically on obstetrics, supports these findings. Four New York hospitals during a 5-year period, reviewed 65,000 deliveries. Researchers found that private patients (22 percent of whom were black) were more likely than clinic patients (47 percent of whom were black) to have a cesarean section, even though the private patients were less likely to have medical problems or to deliver low-birth babies. The disparity between clinic and private patients carried over into a sub-group of patients who were considered to be low risk for a cesarean delivery suggesting that blacks are less likely to undergo a cesarean even when both groups are clinically comparable.

The harm of providing inferior health care services to specific groups has negative results across medical diagnostic categories. The Department of Health and Human Services (2010) reports that compared with the majority populations, United States minority populations have shorter overall life expectancies in a list of illnesses that is both long and alarming. The incomplete list includes cardiovascular disease, cancer, birth defects, asthma, diabetes, stroke, cervical cancer, HIV/AIDS, adverse consequences of substance abuse, and sexually transmitted diseases, and infant mortality. The supporting data from the same (2010) report indicates that the overall mortality rates were 25%

higher for black Americans than white Americans in 2007. In 2006, the age-adjusted death rates for the black population exceeded those in the white population by 21% for cancer, 48 % for stroke, 31% for heart disease, 113 for diabetes, and 786% for HIV disease.

In the framework of general health care, BIM is one of a substantial number of documented poor medical outcomes associated with race and ethnicity (Blanton, et al. 2000). Such disparities in the health status of minority populations have led to new research and policy initiatives. For example, the Office of Minority and Health Disparities report (2005) places the reduction of the overall IM rate as its number one priority of six focus areas, reflecting the goals stated in Healthy People 2010, the nation's health objectives for the 21st century. This goal appears to give recognition of the broad-based societal interventions required to address this population-based problem however, it is a goal that will not be met.

Measuring Stress and Maternal Health Consequences

Cassel (1995) and other researchers suggests that the exposure to a hostile environment may result in psychological stress, which in turn causes poor birth outcomes. The effect of stress on the unborn fetus is becoming an important part of the puzzle in the investigation of the persistent high rate of BIM. How do we measure the presence of stress, how do we determine the kind of stress, and its effect on the mother and fetus, are questions much of the research is attempting to answer. The

construct of stress described below provides a framework for the discussion and review of literature in this section: *Stress is a complex phenomenon that encompasses exposure to psychosocial, environmental, and physical changes and the body's responses to those experiences* (Sapolsky, 1998).

Attempts to understand the complexities of stress and to measure the effects of stress are the focus of a significant amount of more recent research. For example, one study focused on the link between stress and the elevated levels of the hypothalamic, pituitary, and placental hormones, implicated in the initiation of pre-term labor (McLean, et al, 1995).² This research followed by a more extensive study, which examined the cross-sectional association between prenatal psychosocial factors and stress related neuroendocrine parameters during human pregnancy. It concluded that there is an association between maternal neuroendocrine level and certain types of stress, which can influence poor birth outcomes (Wadhwa, 1996). The data found associations between pregnancy related anxiety (pregnancy fears and anxiety specifically related to the health of the baby and the labor and delivery process), and *chronic stress* (the degree in which life situations were experienced as stressful) and neuroendocrine levels. It did not support an

² The hypothalamus and pituitary glands secrete their hormones when they sense that the blood level of another hormone that they control is too high or too low. Pituitary hormones then travel through the blood stream to stimulate activity in their target glands. When the target hormone's level in the blood is appropriate, the hypothalamus and pituitary gland recognize that no further stimulation is needed and they stop secreting hormones. (Berkow, R.1999).

association between *life-event stress* (more episodic in nature, disruptive changes in one's life) and maternal neuroendocrine level over the first two trimesters of gestation.

More recently, research from New York University School of Medicine (2008) demonstrated the link between extreme stress, experienced by the pregnant women, and a higher rate of mental illness among children born. The study focused on pregnant mothers in Jerusalem during the Six Day War, and the findings supported the researchers hypothesis that the second month of fetal development is the one in which the fetus is most vulnerable to schizophrenia-inducing stress. Records of 88,829 Jerusalemites born in the capital between 1964 and 1976, collected from the Jerusalem Perinatal Study, linked to birth records from the Israel's Psychiatric Registry. The children of Jerusalemite women in their second month of pregnancy at the time found to have a higher incidence of schizophrenia 21 to 33 years following the war. Girls born from that sample were 4.3 times more likely to develop schizophrenia as young adults than those born at other times between 1964 and 1976. Boys, however, were only 1.2 times more likely to do so (Malaspina, et al., 2008).

Both of the aforementioned studies make the correlation between stress of the mother and the effects of such stress on the unborn fetus in ways not studied before. The research is attempting to understand what types of stress is harmful to the mother and her unborn fetus. If we

understand what triggers a stress reaction, the effects of the stress on the physiological state, and how this affects pregnancy it may provide a feasible explanation on how to prevent infant mortality.

Mustillo, (2004) sought to validate the association between racism and adverse birth outcomes by interviewing women and examining 352 self-reported experiences of racial discrimination on Black–White, differences in preterm less than (37 weeks gestation) and LBW (less than 2500 g) deliveries, and using logistic regression models, analyzed the birth data among women studied. Among black women, 50% of those with preterm deliveries and 61% of those with low-birth weight infants reported having experienced racial discrimination in at least three situations. Among white women, the corresponding percentages were 5% and 0%. Researchers concluded that self-reported experiences of racial discrimination were associated with preterm and low-birth weight deliveries, and such experiences may contribute to Black–White disparities in IM outcomes (Mustillo, 2004).

Other studies sought to better understand and describe other social stressors, which may contribute to disparities in women's health specifically. For example Shultz, et al (2004) studied women living in an economically disenfranchised urban community, including 48 community residents and 676 women raising children, who were interviewed. Regression models controlling for age, education, and income examined the relationships of each stressor. The strongest stressors, which

emerged from the in-depth interviews, were financial, work, family, safety, physical environment, police, disrespect or unfair treatment. Researchers then tested their hypotheses that each of these stressors individually and cumulatively related to symptoms of depression and general health status, beyond the effects of age and socioeconomic status. Correlations ranged from .099 to .461. The strongest correlations (above .400) were between financial stress and safety stress, physical environment and family stress, and physical environment and safety and police stress. Each of these stressors was significantly associated with increased depressive symptoms and a poorer general health status. Women also reported unfair treatment and disrespect in their day-to day experiences and encounters with health and social service providers. We can conclude from this study that African-American women residing in urban communities disproportionately suffer the burden of disease because of stressors associated with economic divestment, which can result in adverse births (Schulz, 2001).

UCLA obstetrician and gynecologist Dr. Michael Lu (2008), having worked on the front lines for decades stated, "*For many women of color, racism over a life time, not just during the nine months of pregnancy, increases the risk of preterm delivery.*" To improve birth outcomes, Lu argues, we must address the cumulative wear and tear on the body's capacity to handle such stress loads, that affect women's health not just

when she becomes pregnant but from childhood, adolescence and into adulthood.

After Loss: Stress and Implications for Subsequent Pregnancies

The research which focused on women and the psychological aspects of IM following the loss of their infant, sought to gain a deeper understanding of how women and their spouses cope with their loss, with implications for care and subsequent pregnancies. For example, Price (2008) research focused on “reproductive loss” and subsequent parenting, and then recommended four worker-initiated dialogues for integration into social work practice. Van (2001) interviewed 10 African-American women to explore their pregnancy related experiences after pregnancy loss, to describe the perceived strategies these women used for emotionally healing after pregnancy loss, and the implications for professional interventions. Morton, (1996) also interviewed 20 women (two African-American) to examine the psychological effects of 1) on perinatal loss, 2) loss on subsequent pregnancies, 3) the experience of loss on subsequent parenthood, and 4) the loss on life beyond the subsequent child. It is interesting that the literature demonstrates a link between prior pregnancy loss and an increased rate of IM in a subsequent pregnancy, an area of Morton’s research (the experience of loss on subsequent pregnancies). Her focus examined the psychological effects of the loss on the decision making process in relation to subsequent

pregnancy, an area of examination which points to a stress reaction; chronic anxiety related a prior loss (Wadhwa, et al., 1996). Black women with a prior pregnancy loss are almost four times more likely to give birth to another LBW infant (DiNitto, 1991; Rowley, 1994).

Race, Gender and Stress

We know that all blacks, across socio-economic lines live with a certain amount of stress as the result of institutional racism: residential segregation, political disempowerment, employment discrimination, etc. For black women there are other exasperating factors including gender, which makes her especially vulnerable to elevated levels of stress and health risks. According to Root (1992), *“Many women of color are leading middle-class lives, thus apparent economic barriers are not as formidable, the others remain; social and institution barriers remain astonishingly similar, founded again in the intersection of subordination of the female gender by race.”*

Stress and its link to preterm births and failed Black infant births, may be the most significant differentiating factor in the disparity between black and white infant mortality rates. The research demonstrating a link between stress and adverse birth-outcomes is significant (Hoffman, 1996; Lederman, 1995; Lobel, 2008; Lu, 2008; Wadhwa, 2001). It is important to value the women’s experiences with stress, the sources of stress and the coping mechanisms employed, to

understand the apparent results of stress for the women. It might be helpful to refer to concepts, which place stress in both an individual, social and historical context.

Allostatic load is one such concept and describes comprehensive and cumulative risks across multiple physiological regulatory systems resulting from chronic exposure to life challenges or stressors that influence health outcomes across the life span (McEwen & Stellar, 1993; Seeman et al., 2002). Allostasis is the body's ability to maintain homeostasis and adapt to acutely stressful events, and when challenged in situations of chronic or frequent stress, or when there is an excessive demand on the body's regulatory systems (McEwen, 1998; Lu, 2003). In other words, one concept relates to the physiological capacity to handle stress, while the other refers to the equilibrium mechanism. Another perspective on cumulative health risk is the concept of "weathering." This too provides an explanation for potentially greater susceptibility to stress among Black American women compared to White American women. The "weathering" construct suggests that Black women experience deterioration in health because of the cumulative impact of repeated experience with social, economic, or political exclusion. This increases her vulnerability to adverse birth outcomes (Geronimus, 2001). Such concepts provide a plausible perspective in understanding the BIM phenomenon.

An increasing number of studies are supporting the notion that there is a surprising price for being a black woman in America (Drexler, 2007). For example, one study examined the association between a composite index of stress that included measures of life events, ongoing stress, discrimination, and economic hardship and carotid disease (a precursor to heart disease) among 109 African American and 225 Caucasian pre-menopausal women. The African- American women reported more stress that was chronic and developed more plaque in their carotid arteries as compared to Caucasians. Among African-Americans only, the composite stress index and unfair treatment were associated with higher carotid arteries. These effects were partially mediated by biological risk factors; however, those who reported experiencing racial discrimination had slightly more carotid plaque than did those who did not report experiencing racial discrimination. African- American women who identified racism as a source of stress in their lives developed more plaque in their carotid arteries (an early sign of heart disease) than black women who did not. The results suggest that Black- American women may be particularly vulnerable to the burden of chronic stress (Troxel, Matthews, et al., 2003).

In the documentary *Racism Harms Your Health* (2008), the theory that racism as a chronic stressor with deleterious health consequences is gaining significant attention in understanding the possible reasons for the disparity in black and white IM rates. Researchers are convinced

that everyday exposure to racism puts one's body on alert, similar to a stress response, but in this case, the stress response is turned on for a lifetime, which takes a toll on the body. This theory addresses the question of why Black- American women may be more susceptible to maternal stress with higher rates of poor birth outcomes and is aligned with the Allostatic load and "weathering" concepts (McEwen, 1993; Geronimus, 2001).

Other research support findings on the perceived experiences of racism across socioeconomic groups of Black Americans and has implications for maternal health. Thompson's (1996) study consisted of 196 participants (114 females and 82 males), eighteen years and older, residing in the St. Louis Metropolitan Area. The median age 33.5 for males and 34.0 years for females with a median income of \$23,000. More than 37.2% had some college, 14.3 were college graduates, 17.7 had some graduate education, 20.4 completed high school and 10 % failed to complete high school. The Impact of Events scale (a measure of subjective distress in response to a specific life event) and the Racial Identification scale were tools used along with a subscale to examine the individual's sense of concern and commitment to the racial group. The participants completed a questionnaire, which requested information on experience with racism within six months of the interview. The results indicated that almost 34 % of the participants reported perceived experience of racism within the six months of the interview (one-third),

with no significant differences in reporting by sex, education or income. Mean scores of avoidance and intrusion symptoms suggested that individuals' experienced subjective distress. Episodes of intrusive thinking and periods of avoidance were noted. The intrusion symptoms were higher as the seriousness of the event increased. Findings revealed that even recalling perceived experience of racism produced significant stress, across socioeconomic levels.

It is important to highlight the fact that during the course of a lifetime one may be fortunate enough not to be the victim of racism at some given time. However, the fact that there is the distinct possibility that because of one's race it could occur at any time can create stress above the "generic stress" of life (Harrell, 2000; Jackson, 2007).

Historical Framework in Examining Stress

An important question that emerges from a discussion on stress as it relates to black women and her maternal health is: *to what degree has America's history and the Black-American woman's experience therein, shaped her perception of self; and with what consequences?*

There are beliefs, behaviors, and attitudes, linked to the black woman's history in America (Root, 1996; Solinger, 1993, Degruy, 2005, Hendl, 1995). Such a history has gradually become, in varying degrees, the custody of her sense of self, and her responses to the "outside" world with complicated results. Research demonstrates the consequences of

racism, which traumatizes, hurts, humiliates, enrages, confuses and does measurable physical and psychological harm (Harrell, 2000; Troxel, et al., 2003; Bromberger, et.al. 2003) are layered with coping mechanisms, which may have origins in a racial history. For example, the ability to “stand up to the rigors of work,” regardless of physical frailties is a common theme of black professional women, traced to historical negative attitudes about black women especially in relation to motherhood (Herndl, 1995; Solinger 1992). Except for the initial ceremonies bestowed upon a black mother during the announcement phase of her pregnancy, what normally follows is *business as usual*, and needing to be viewed as able to carry out *business as usual*.

Characterizations such as the strong, maternal workhorse “Mammy,” which dominates even contemporary representations of black women, have affected the black women’s perception of self in complicated ways (Herndl, 1995). Add to these historical beliefs of what childbearing for black women represented -economic gain- an underlying view still evident in many of today’s stereotypes (Solinger, 1992).

Terri Williams (2008) writes – “*I have come to believe that as Black women our threshold for pain is too high. We have embraced very destructive beliefs about our ability to ‘handle it all,’ our power to overcome in the face of trauma, our ability to put ourselves aside as we tend to the needs of our employers, partners, children, family – everyone but ourselves.*”

The responses of black women to historical stereotypes and racist views have not been easy to decipher. Black women, and their mates, seem to have accepted the notion of the black woman being an indestructible “workhorse” needing to prove a standard of worth in an attempt to shed haunting past held views (Herndl, 1995). However, such acceptance adds to the consequences of stress. For example, in studying the effects of sexism and racism, Krieger (1990) discovered that African-American respondents were 5.9 times more likely than white respondents to keep quiet and accept unfair treatment in the course of daily activities (at school, work, getting a job, getting medical care). Additionally African-American women who said they accepted unfair treatment without complaining were 4.4 times more likely to report having high blood pressure than those who talked to others or responded to being treated unfairly. Other authors would suggest that the absence of complaints (silence) about unfair treatment does not suggest acceptance. It might be a means of resistance against feelings of oppression (Roberts, 2000). In either case, the stress is present.

Treating the consequences of stress is another challenge. The Department of Human Services: Mental Health Supplement (2001) report indicates that only 16 percent of African Americans with diagnosis of mood and anxiety disorders saw a mental health specialist, and less than one-third consulted a health care provider of any kind. Disparities between African Americans and whites also exist after initial accesses to

care barriers were removed. Additionally, after entering care, African Americans were more likely than whites to terminate treatment prematurely.

Conclusion:

The literature presented in this chapter includes the socioeconomic variables (poverty paradigm) typically attached to understanding the disparity between black and white infant mortality rates. The review also includes research reflecting an emerging perspective on the role of racism linked to stress, revealing how social factors interrelate with biologic and psychological factors may explain the disparity rates in LBW, preterm delivery and infant loss among Black American women.

The areas covered in this literature review included, the prevalence of premature and low birth weight (LBW) and its link to Black Infant Mortality (BIM), the strength and weakness of the socioeconomic variables linked to LBW and BIM. Additionally, a review of individual risk factors and efforts implemented to manage risks, the debatable role of prenatal care in reducing LBW and BIM, and benefits and weaknesses comprising the patient/physician relationship.

The major current research trends in the examination of BIM include, institutional racism and its affect on health disparities, understanding and measuring the effects of stress in relation to maternal health, race

and stress and implications for BIM. In addition, the review includes an examination of the role of a racial history and its relevancy to BIM.

What is missing from the literature is the black woman's voice. The pregnancy stories of the women who have lived the experience are missing from the research. Especially those, with all things being equal, should not be at higher risk for adverse pregnancy outcomes. Much of the research focused on black women of lower socioeconomic status, and/or women who have not had direct experience with infant loss. African American women provide a unique perspective of self, society, history and culture. To include their self-defined experiences will add an important layer to the discussion of BIM phenomenon with implications toward better solutions in reducing the racial gap in infant mortality.

The next chapter (III) presents the research design and the procedures used in conducting this qualitative research study on Black Infant Mortality.

CHAPTER THREE

METHODOLOGY

Introduction

Research Question:

Given the disparity in the infant mortality rates among middle class black and white women, are there factors attached to the pregnancy experience of middle class black women, which could help in understanding the adverse birth outcomes for this target group?

This multicase study, with a sample of eight Black-American women, is guided by this research question. The researcher believes that the findings of this study identifies areas for further research to gain a deeper understanding on those factors contributing to the persistent high rate of black infant deaths.

This chapter describes the research methodology and includes information and discussion in the following areas: rationale for research approach, research sample, overview of design (steps used in carrying out research), methods for data analysis, protection of subjects, issues of trustworthiness of data, limitations of study, and a concluding summary.

Rationale for Study Methodology

The inability of quantitative research efforts to isolate a single cause for the persistence of the black-white gap in infant mortality suggests that the problem has many causes, some of which cannot be determined by population based studies. Few studies have explored BIM with the women who suffered this kind of loss, with the aim of hearing a robust account of their entire pregnancy, and the salient factors surrounding and affecting their pregnancy experience. Similar studies have focused on the bereavement process following the loss (Morton; 1996; Van, 2000), and on perspectives of black women on BIM (Barnes, 2008) but not on the “pregnancy story” from women who have lived the experience. This study has an phenomenological perspective, which is attempting to understand the essence of the experience from the people who have lived it (Patton, 1990).

This study uses qualitative methodology, which is well suited for the more subtle dimensions involved in this topic, and asked women to reflect on their pregnancy experiences. This study is exploratory in nature and inductively and holistically aimed to understand the experience of a specific group rather than test theoretically derived hypothesis. This study’s goals were to explore and generate new concepts and constructs that will add a deeper understanding of the problem (BIM) through personal in-depth interviews. The emphasis is

on the lived experiences of the women in relation to their pregnancies, and in understanding the meaning of pregnancy from their perspective, the context surrounding their pregnancy, their perceptions, and feelings, and how all of these factors connect to their outside world. Qualitative data are “fundamentally well suited” for this type of emphasis (Miles & Huberman, 1994).

This research targets self-identified black women born in America, ages 25-40, middle-class and married, thus eliminating socio-economic and access to medical care issues, which will help to surface new information specific to this group.

This study identifies areas for qualitative research, with the same or similar target groups, to deepen the understanding of causes of the disparities in order to contribute to education, public awareness and to health and mental health intervention approaches specifically for black expectant mothers, and those planning to have a baby. This study offers a qualitative grounded perspective on an issue, conventionally examined through quantitative methods. It does not seek to generalize beyond the target group (i.e. blacks from other countries living in America).

An important goal of this research is to reduce the “disjunction of grand theories with local contexts.” (Guba & Lincoln, 1994). In other words, what meaning do the current theories or research findings and assertions hold for the individual woman who has suffered the loss of her infant, and in preventing a future loss? As Mintzberg, (1983) points

out in his discussion around the need for “rich description,” that so many relationships are uncovered in the “hard” data, but it is only through using “soft” data are explanations provided. These “rich descriptions” also contain accounts given in the words of the participants, which add a dimension of power to the data, which is difficult to discount (Patton, 1990). Personal statements have face validity and credibility, which may add to the findings of quantitative studies in unpredictable ways.

The important point here is that this research intends to add and offer a grounded perspective to an issue conventionally examined using quantitative methods, through the lens of a “poverty” paradigm, conventionally used to study BIM. This qualitative approach is particularly appropriate since the information gained through quantitative studies reviewed have answered the question *what* is occurring, but not *why* it is occurring, and has failed in positively affecting the rate of the disparity between white and black infant deaths. Additionally, the compatibility of the qualitative design with the goal of this research seems appropriate since the inductive character of the qualitative method values open-ended inquiries to encourage the sharing, in this case, of the individual’s pregnancy story. It is through the interviewing process that a personal perspective is gained and new information may be uncovered (Patton, 1990). Qualitative research, through personal contact, will allow closeness to the women and the use of researcher’s personal experience with the phenomenon, (empathetic

neutrality). (Patton, 1990) adds strength to the interview in seeking information, and to the interpretations of the material. The material gained in personal contact, with the flexibility to delve into areas surfaced by responses, allowed those elements to come into play which are not measurable (i.e. intuition), and which would only probably surface because of *being there* with the individual (Mintzberg, 1983). Qualitative method is useful in this research project, as it is an appropriate method in examining relatively new terrain from a subjective, exploratory stance (Epstein, I).

Additionally, the timeliness of this project is of particular importance, as health care reform is a high priority item on our nation's agenda for change. The Office of Minority and Health Disparities (2005) placed the reduction of the overall IM rate as its number one priority of six focus areas, reflecting the goals stated in Healthy People 2010, the nation's health objectives for the 21st century. By this year 2010, the goal is to eliminate disparities among racial and ethnic groups with infant mortality rates above the national average, a goal so far unmet. The Institute of Medicine (2006) reports that no test can accurately predict preterm births, and little is known about how preterm births can be prevented. The same report, along with other researchers, highlights the need for research by a range of disciplines to explore the reasons for disparities between black and white IM rates (Jackson, 2007; Rowley, 2001; Barnes, 2008).

Sampling Procedures

The study used purposeful sampling to select participants. To yield the most information about the problem under study, purposeful sampling is a method typically used (Patton, 1990; Silverman, 2000) in order to select information rich cases for in- depth study. The unit of analysis was selected based on its connection with the main research question:

Given the disparity in the infant mortality rates among middle class black and white women, are there factors attached to the pregnancy experience of middle class black women, which could help in understanding the adverse birth outcomes for this target group?

Members of the sample have lived through the particular event (the death of an infant) (Patton, 1990), and the specific target population has suffered disproportionately. Eight self-identified Black-American women participated in this study. The sample size provided sufficient opportunities for comparing a range of responses as important information surfaced (Stake, R.1994), but the data, collected from a limited number of individuals was not representative of all black women who experienced infant loss and therefore are not generalize- able(Patton, 1990, Miles & Huberman, 1994). Researcher narrowed the unit of analysis to middle-class self-identified Black-American women, a sub- group not sufficiently studied, with twice the BIM disparity rate as their

white counterparts, and whose experiences do not fit the explanations offered by viewing the issue through the conventional “poverty paradigm”.

The criteria for selection in this study are listed below:

- Self-identified black-American born women
- Between the ages of 25 and 40
- Experienced the death of an infant
- Married
- College graduate
- Employed/ middle-class status

The study initially had a time limit between the event (loss of an infant) and the interview. However, a few of the women expressed an interest in participating in the study that experienced their loss outside of the stated period. The criteria was reviewed and eliminated, as the importance of including women who had direct experience with the event was deemed more important than the time issue. Moreover, the modification did not change the aim of the study nor did it appear to weaken the findings. The average time between the time of the interview and infant loss is five years.

An array of sources and various approaches were used to recruit subjects, including social networking, snowball sampling and advertising, to secure the desirable sample. Agencies contacted were those in direct contact with women who had experienced the loss of their

infant (i.e. Northern Manhattan Perinatal Partnership, Northern NJ Maternal/Child Health Consortium, Cathedral International, one of the largest congregations, consisting of African-Americans, etc.). Personal contacts initiated with professionals who sent out recruitment letters to their listserv groups, representing several thousand contacts. In addition to emails, flyers were posted at numerous facilities, including OB/GYN offices throughout NJ., and on the recommendation of Public Health Solutions (NYC), a web-site to support recruitment efforts www.blackinfantmortality.com was created. Researcher attended several conferences and meetings to disseminate information to professionals serving the study's population.

The recruitment results revealed that the most effective approach was very personal. Two of the respondents were generated because of researcher's attendance at a professional meeting, 3 from emails to professionals, who in turn made referrals based on personal contacts with women fitting criteria. Two other subjects gained through snowballing, and 1 was originally part of an unpublished pilot study conducted by this author (same topic), who was re-interviewed for inclusion at her request. In all, about 12-15 women contacted researcher who wanted to participate, but misunderstood the nature of the study (most had high-risk-pregnancies). There were about 3 women who indicated an interest in participating, who did qualify, but researcher could not reach. Part of the recruitment challenge was needing to rely on

others to convey the initial “message” making it that much easier for women not to follow-through. Numerous professionals in the field confirmed that they too find it very difficult to get women to come in for services, outside regular prenatal care visits, which is an interesting factor when figuring out effective education efforts in dealing with BIM. It must also be noted that the particular population targeted for this study (educated, middle-class, married) are not easily accessible, as they are usually seen for prenatal care privately, and are not the most prone to talk about this very personal and emotionally charged event.

Sample Characteristics

All of the subjects were self-identified black women born in America. The respondents were all in their early to middle thirties at the time of their loss. All of the respondents were college graduates, two possessing Master degrees, and one Post-Master degree (MD). They were all working full-time at the time of loss, with the exception of 1 who stopped working during her second trimester. All of the participants were married, with gainfully employed spouses (Appendix C).

None of the women suffered prior infant losses. None of the women reported any pre-existing medical conditions for themselves or their spouses, with the exception of one spouse who was on medication for high blood pressure. One woman was in a marriage with an abusive spouse.

There were one prior pre-mature births (three weeks early), and two terminations. Six of the respondents had children prior to their loss; three had 1 child, two had 2 children, and one had 3 children. Four of the women also had children after their loss. Four of the women experienced their loss at the end of their second trimester, and four experienced their loss in the third trimester (Appendix C).

Five of the interviews were held in the respondent's home, 2 were arranged at their work places (no interruptions occurred), and 1 respondent lived in Atlanta, Ga., therefore the interview was conducted via telephone, and was audio taped.

Overview of Research Design

The following list summarizes the steps involved in carrying out this research followed by a more in-depth discussion:

- Review of the literature preceding the actual collection of data, which included the contributions of other researchers and research trends.
- IRB application followed the proposal defense. IRB granted for research on human subjects.
- Potential research subjects were contacted via telephone to explain purpose of the study, and to qualify subjects for study. Time for interview established during this call.

- Eight interviews conducted with women who had direct experience with the BIM guided by a semi-structured interview guide.
- Researcher transcribed all audiotaped interviews; synthesized and analyzed material.

Literature Review

A review of literature relevant to this project was conducted in preparation for this study. The review included a historical framework, theories related to social and socioeconomic variables typically attached to this topic. Additionally, the research review included an emerging body of research, which offers a newer perspective on the role of racism linked to stress, suggesting the interrelationships between social factors with biologic and psychological factors, in examining LBW, preterm delivery, and infant loss among Black American women. Of note, the overwhelming majority of the research was conducted with poor African-American women. Other qualitative research, which included black middle-class women as part of the research sample, related to the topic but focused on maternal issues after infant loss (bereavement, subsequent pregnancy)(Van, 2001;Price, 2008), or on the black women's perspectives about BIM from women whom did not live the experience (Barnes, 2008). Very little information exists which places the black female who lived the experience at the center of the research. As well,

very little material exists pertaining to the fathers (Quinn, 2008; Frey, 2008).

It is important to note that that the emerging theories around stress, and deleterious physiological responses, which affects birth outcomes, although feasible and measurable, fail to explain why most black women with the same or similar experiences have successful pregnancies and deliveries.

IRB Approval

Institutional Review Board (IRB)(full review) received application submitted to Hunter College Committee for the Protection of Human Subjects. Application approval occurred on 11/28/2008, and renewal on 11/19/2009. The researcher successfully defended a proposal for this study that included: the historical background/context, problem statement, the literature review (included in chapter II), and the methodological approaches contained in this chapter.

Contacted Participants

Researcher contacted participants via telephone after they indicated an interest in participating in the study, usually via an email correspondence. The telephone contact was an important opportunity to begin to establish a rapport with the women and set the stage for the

one-on-one interview. The Recruitment script guided the communication, intended to make sure that the respondent met study's criteria, understood the purpose of the study, and the anticipated time commitment for the interview. There was a check off section, which was at the end of the Recruitment Script containing questions related to demographic data, financial status, and the number children.

In the case of the subject, whose interview was conducted via telephone due to distance, this contact with participant was expanded. Researcher determined the necessity of covering the identification of a "private" place during the interview time, and making sure, that the time allotted was sufficient for the interview. The expanded conversation also substituted, to the extent possible, for the rapport-building phase that usually occurs during face-to face contact.

Data Collection

Data were collected for this study spanned from late December, 2008 through late August, 2009. The primary source of data was generated through an in-depth audiotaped interview, lasting from 2.5 to 3 hours using a semi-structured interview guide (Appendix B), with numerous subsequent phone contacts. The guide consisted of eighteen open-ended questions broadly covering internal and external factors including: meaning of pregnancy, health and medical care issues, experience with stress, sources of stress, and coping behaviors, support

system (context), personal behaviors practices, events and feelings, and the respondent's reflection and thoughts on why her loss occurred.

All of the questions contained in the semi-structured interview guide (also known as an open-ended format) related specifically to the phenomenon, and reflected areas studied and discussed in the literature review (chapter II). A statement concerning researcher's wish to learn more about the issue from the women who lived the experience introduced the questions. The guide allowed for varied nuances of expression and meaning, as the questions aimed at surfacing feelings, thoughts, recalling actions and behaviors, and in helping to describe the pregnancy experience in-depth. The interview guide consisted of a number of questions worded precisely. However, there remained opportunity for the researcher to probe, and make decisions about what topics to explore at greater length, as responses by subjects often contained natural associations in the ebb and flow of the conversation. This allowed for exploration on matters not contained in the guide. The interview guide also made data collection much less complicated as the format made data location quicker and the organization of answers and themes easier.

The interview guide used an informal conversational approach, and probes were interjected when needed. The flow of areas of inquiry generally coincided with the natural sequence of events of a pregnancy

(i.e. preplanning, discovery, prenatal care, etc.) however, the flow of the inquiries were also determined by the responses of the subjects.

Miles & Huberman (1994) state that triangulation “is not so much a tactic as a way of life.” This researcher double-checked findings using multiple sources and modes of evidence as the study progressed. Therefore, the verification process was largely built into data collection. Sources of data, which supplemented the interviews, included “slices of data” (Strauss, 1987) from an unpublished study by this researcher (2001), and a documentary featuring one of the participants (subject living in Ga.). Researcher attended conferences convened by medical experts in the field, and held discussions on findings with professionals in the field and black mothers, along with the continuous review of pertinent qualitative and quantitative research.

Analysis and Synthesis of Data

Qualitative analysis is usually in the form of words rather than numbers. Therefore, it is in the asking about the event- *pregnancy story* - that data was uncovered and collected. This study is exploratory in nature and the research goal was to better understand those factors present in the lives of the black, middle-class women in this study, which contributed to their adverse birth outcomes. This is of particular interest, since the logical assumption would be that if all things were equal; this group should not be at a higher risk for infant loss, but they

are. This part of the BIM phenomenon is not well understood and helped to guide choices in relation to areas of exploration (Miles & Huberman, 1994).

The guide, primary data collection tool, reflected salient issues coming out of the literature review. Changes to the guide were made because of recommendations made by the Institutional Review Committee. The Committee recommended fewer questions designed to elicit spontaneous responses. The concern was to lessen the degree of personal intrusiveness by the researcher, which could be psychologically harmful to subjects given the sensitivity of the subject matter. Nonetheless, the open-ended exploratory questions encouraged participants to speak quite candidly and openly about events surrounding their pregnancy.

Researcher decided not to use research software, as the sample size was viewed as manageable. Researcher transcribed the taped interviews and listened to the responses often, becoming immersed in the material, and gaining an understanding of the uniqueness of the individual cases before combining and comparing findings with the larger sample (Patton, 1990). Researcher first reviewed responses in relation to the questions asked, to make sure that the questions accurately obtained the information it was after. The initial line-by-line coding gave way to the identification of bigger chunks of data containing themes and patterns. The conceptual framework of this study (meaning

of pregnancy (preplanning and discovery stages), health and medical factors, experiences and sources of stress, thoughts (reflections) on why the loss occurred) provided the core categories for the repository for the data relating to these categories. Initial descriptive codes were assigned to relevant quotes. Simultaneously, data summary matrices were constructed. Refining of coding and the filling out the data summary tables (matrices) were done in tandem. It was important to allow the material from the interviews to guide the search and decisions regarding themes and patterns, categories were expanded or collapsed as connected threads surfaced from the data (Miles & Huberman, 1994). Questions were constantly asked by researcher in exploring alternative conclusions and for deeper meanings in the material. Researcher recorded such questions and thoughts about the material in a journal. Such questions often lead to the identification of new categories and/or the refining and/or the elimination of others. Attention was given to words, significant phrases, and feelings attached to words. The tone and intent, however usually heard in the accounts, as the thick descriptions in the women's own words allowed entrance into their world.

A user-friendly Contact Summary form used to help researcher identify those areas of particular interest/concern to the interviewee, areas stubborn to penetration, areas needing further exploration, new discoveries, and/or researcher's strength/weakness. Fore example, following the first interview it was noted that a heightened degree of

self-monitoring around providing input on certain issues regarding the phenomenon would be required to maintain a stance of neutrality (Patton, 1990). Researcher was in the role of helper rather than researcher. The completion of this single sheet form took place immediately following the interviews.

In working alone, it was important to record internal conversations with regard to the research (Strauss,1999) which captured researcher's thoughts, hunches, questions, ideas etc. Researcher found it most useful to make such notes on the margins of the transcriptions next to those events, statements, etc. which triggered the researcher's response. The descriptions of findings are reported under the areas of exploration (conceptual framework), and provided answers to the four research questions, discussed on page 86. The final phase involved the synthesis and interpretation of the data, in ways that the data could be understood, in a speculative manner, as this issue is complex and cannot be understood in a linear cause and affect manner.

Protection of the Respondents

Ethical issues, especially for research involving human subjects are of vital concern (Berg, 2004; Marshall & Rossman, 2006). It was the researcher's responsibility for both informing and protecting subjects. The researcher successfully enlisted those respondents who voluntarily

agreed to participate in this study and informed each respondent about the study's purpose and the central issues surrounding their protection.

This research was conducted in accordance with a full review made by Hunter College/Institutional Review Board, this research approved on 11/24/2008 and the IRB renewal granted on 11/19/09.

Each participant prior to all interviews signed and reviewed the Informed Consent and audiotapes permission letters, and copies the signed documents are in their possession. All of the participants were assured that their information would be kept confidential, and their identity would remain anonymous. Personal identifiers were replaced with numbers and fictitious names. No personal identifiers are linked to the data.

Researcher initially introduced herself to each participant via telephone utilizing the Telephone Recruitment Script, which described the nature of the study, the time commitment, and qualified the subjects for the study. Both during the initial phone contact and the face-to-face interview the researcher highlighted the voluntary nature of the subject's involvement, and the steps to ensure confidentiality. The respondents were informed that they could stop the interview at anytime, as researcher was sensitive to the emotionally charged nature of the material.

The researcher audiotaped interviews with subject's signed permission. Researcher transcribed all audiotapes and destroyed

audiotapes following transcription of the interviews. All records pertaining to this research will be securely kept in researcher's home office in New Jersey in a locked file cabinet, and computer files safeguarded by password protection. The information gained from this study is for the production of a doctoral dissertation, and may be included in publication for articles in professional journals. Omitted or disguised identifying information on the subjects and others, who participated in the study, provides safeguards to ensure protection. Upon completion of this study, the paperwork will be stored in a locked file cabinet for up to three years, after which time all original completed notes on questionnaires will be destroyed. As long as the data exists, it will be kept secured.

The researcher reviewed with each respondent and left behind a list of resources and services prior to ending the interview. A debriefing script used at the end interview, was designed to encourage questions, address any concerns, and to express appreciation for subject's participation. It was important for the participants to view the interviews as conversations to be continued, as the content of each interview or conversation gives form and substance to the next one (Schatzman, & Strauss, 1973). Respondents were therefore, asked permission for researcher to make subsequent contacts via telephone for clarification and/or additional information. All respondents agreed, and such follow-ups occurred.

Issues of Trustworthiness

Trustworthiness features in qualitative research consists of efforts made by the researcher to address the degree to which something measures what it claims to measure, and the consistency with it measures it over time. These features of research, traditionally found in quantitative research, are used to measure validity and reliability of the data. Guba & Lincoln (1998) argue that qualitative research should be assessed differently from quantitative research and use different terms in addressing the issue of trustworthiness: credibility, dependability, confirmability and transferability. Regardless of the labels or terminology, the idea is to control, to the extent possible, potential biases that might be present throughout the study, from design to analysis.

Credibility

The criterion of credibility suggests that the findings are accurate and credible from the standpoint of the researcher, participants and reader. From the beginning of this study, the researcher explored answers to four related research questions:

- *Are there variables attached to early pregnancy preplanning and discovery stages, which helped to shape the entire pregnancy experience, contributing to poor birth outcomes?*

- *Are there factors or issues imbedded in the black middle-class female experience, related to health issues and medical interventions, which could help in understanding the adverse birth outcomes for this target group?*
- *Are there unique experiences with stress, which might offer some understanding of the poor birth outcomes for this target group?*
- *Are there unique experiences, feelings, or thoughts, explicated by the participants' reflections on the occurrence of infant loss, which might add to understanding the adverse birth outcomes for the women in this study?*

This approach tested the logic of the method in relation to the kinds of material that the research questions surfaced, and the intent of the study. The point here is that the methodology was consistent with the intent of the study, and findings satisfactorily addressed each research question. This was an initial step in the addressing the issue of credibility (Mason, 1996), and researcher, through the design of the study, enhanced the credibility of the results.

The women in this study were asked to revisit a space and a time where a loss was experienced, and to recall the context in which that loss took place. Although, there was initial concern that the women might experience memory lapses, avoidance or discomfort in recalling such a painful event, what seemed to be clear during all of the interviews was a sense of wanting to tell their story (Morton, 1996). It was also clear that

they had not told their stories, in its entirety, prior to this interview. Some of the questions and probes were successful in triggering memories of details previously forgotten. The richness and thickness of the descriptions have face validity and credibility (Patton, 1990), were convincing, and enables a “vicarious presence” for readers (Miles & Huberman, 1994). It was in these thick descriptions with many details, that meanings surfaced linked to themes identified in the research, and in discussions with black women outside of this research, which added to the internal validity of this study (Paton, 1990).

It is true that the researcher has some personal familiarity with the area of study, and therefore, she sought to exercise caution in maintaining a stance of “empathetic neutrality.” Additionally, the researcher’s professional training as a clinical social worker, assisted in facilitating the process for participants to share highly sensitive material. Patton (1990) points out that the need for a researcher to maintain a neutral stance does not mean detachment. The researcher was aware that her experience with the issue, which assisted her in being an active empathetic listener and helped in posing probes that, facilitated important and relevant responses. Researcher was also alert to biases because of her identification with sample.

The recall in relation to the details of the pregnancy for all of the participants was impressive, although there were times when

remembering specific dates were challenged. However, it is likely that the significance of this event for each woman enhanced the overall level of recall (Hogman, 1985), and the entire pregnancy story was captured with solid accuracy as suggested by their detailed accounts. All of the women were forthcoming with information, although at times, recalling the event seemed especially emotional for two. However, at no time did the researcher have to stop an interview, although pauses were made throughout to check on how the subjects were handling their emotions. There was clearly a cathartic nature to these interviews for the women adding to the plausibility of their accounts.

Dependability

The traditional quantitative view of reliability based on the assumption of replicability or repeatability. It asks would another researcher obtain the same results if repeated with the same set of respondents? In quantitative research, reliability assumes that replication of the testing procedure is possible and there is an observable regularity about human experiences that is a function of those experiences, and not of the testing procedure (Sandelowski, 1986). As stated by Lincoln and Guba (1985) the most important issues is whether or not the findings are consistent and dependable with the data collected. The data collection tool used in this study contained the same open-ended questions (Miles & Huberman, 1994) which assisted with reliability, as it assured that all subjects were responding to the same questions.

This researcher made a concerted effort to be consistent in the coding of the data, and to keep a check on the internal decisions about themes and other data. Researcher made a conscious effort to be aware of her identification with subjects and to bring professional discipline and self-monitoring to bear on the process, so to obtain reliable results.

Confirmability

Confirmability equals objectivity in quantitative research. The implication is that the findings should reflect the research not the subjectivity or biases of the researcher. To achieve this it is important for the researcher to be transparent with regard to decisions and ongoing reflections are noted through journaling in relation to interpretations of data.

Paton (1990) explains that over time the exploratory process gives way to the need to confirm the importance and meaning of emerging data, which involves testing ideas and confirming the meaning and importance of patterns with new cases. The broader issue is to ensure that the findings are coming out of research, and not out of researcher's biases, often evidenced in making inferences (Yin, 1984). It is true that the researcher's experience with the topic resonated with the accounts shared by the women. There was constant questioning with regard to inferences based on identification with the targeted sample. This tension was recognized throughout the project; however, researcher was aware of the need to self-monitor and constantly questioned conclusions and

interpretations. However, the detailed and powerful descriptions spoke volumes, which helped to maintain a level of objectivity. The clarity of the women's words could not be discounted, which provided the basis for making connections and in the identification of themes. Nonetheless, the researcher was cautious about making inferences or imposing her framework and sought patterns in the data among the sample and from other sources to confirm findings.

Transferability

External validity or transferability refers to the degree to which the results of qualitative research are generalizable or transferrable to other contexts or settings (Guba & Lincoln, 1985). Generalizability was not the intended goal of this study. With regard to transferability, it is likely that the findings in this study are applicable to other black women who experienced an infant loss. The characteristics of the sample are fully described to provide comparisons with other groups. The "thick descriptions" provided in this study allows readers to "assess the potential transferability, appropriateness for their own settings" (Miles & Huberman, 1994), and to assess if the responses resonates with the reader's own experiences. This study provides detailed information, through the respondent's own words, about a small and specific sample to increase understanding that may be used to formulate problem-solving approaches following more corroborating studies. While commonalities

of the respondents' experiences need to be understood, it is not useful to generalize experiences that are not generalizable (Field, 1994).

This is an exploratory study; it aims to explicate important constructs for further research of black women of the same or similar socioeconomic status, with the same lived experience in relation to infant loss, prior to generalizing results.

Limitations of study

This was not an agency-based study, therefore the recruitment of subjects was challenging given the sensitive nature of the study, and the inability to have direct access to members of the desirable sample. The sample size is relatively small, and may limit the breath of the responses. However, to counter this limitation, researcher sought in-depth interviews reflected in the thick descriptions, which provided sufficient material for comparisons between the subjects, and explicated themes and possibly new findings for corroboration.

As mentioned, the reflective nature of this study would suggest opportunities for inaccurate information, and the distance in time from the event, subsequent pregnancies, or no subsequent pregnancy could all have an affect on the responses and on memory. There is no ideal situation for the collection of data with regard to this topic, as each approach has limitations. For example, if the interview had occurred soon after the loss, feelings of grief and/or blame could have skewed or

overshadowed the responses. The limitations with regard to accuracy in recall was addressed to the extent possible, by checking for incorrect information, in returning to areas where any level of confusion existed, and in some instances by asking the same question in a different ways to check the accuracy of the memory.

One of the key limitations of this study (inherent in qualitative research) is the issue of subjectivity and researcher bias. As discussed, the researcher was acutely aware of her own biases and identification with the women in this study. On the other hand, the question on who the researcher *is*, and how this may have affected the responses, also deserves consideration. Although some of the respondents asked about the reason for researcher's interest in the study, in every case the question did not come until the end of the interview. Therefore, this piece of information did not affect responses; however, race and probable assumptions about status may have affected the responses in ways that were not readily detected by this researcher.

Conclusion

The disparity between black and white IM rates continues to baffle researchers and professionals on the front lines. Exploration of why this problem is occurring amongst a sub-group of black women, who are educated, married, have access to medical care defies what researchers thought they knew about this phenomenon. This study aims to go deeper

into the pregnancy experiences of black middle-class women, who have lived through the loss of their infant. The women in this sample should not be at high risk for adverse pregnancy outcomes. Their pregnancy stories explicate material for increased understanding, and identifies areas for additional research.

The next chapter, IV starts the presentation of the findings with the *meaning of pregnancy*.

CHAPTER FOUR

FINDINGS

THE MEANING OF PREGNANCY

This research enters each pregnancy experience at the beginning, through the recollections of eight black American women who candidly shared their personal pregnancy stories starting from the pre-conception to the discovery stages of their pregnancies. The exploration starts with the question - *are there variables attached to early pregnancy preplanning and discovery stages, which helped to shape the entire pregnancy experience, contributing to poor birth outcomes?*

The pregnancy story begins by identifying events surrounding the early stages of the woman's pregnancy that inevitably shaped the entire pregnancy. The themes relate to the woman's reasons for wanting to become pregnant (her decision), was the pregnancy planned vs. unplanned (wanted vs. unwanted), what key events occurred during this time frame, what kind of support system did she have, along with an integration of the woman's feelings and attitudes during these important periods. These pre-pregnancy periods become an important part of the pregnancy story, especially for women who suffered the loss of their child.

Five major findings emerged associated with meaning of pregnancy. The first finding revealed that the majority of the women (6 out of 8) made a personal decision about childbirth prior to joint planning with

their spouse. This personal decision made by the woman could lead to possible consequences if the decision does not match the practical realities of her family's circumstances. In one case the decision was not to have more children (Alana). However, the majority of the women (5 out of 8) then proceeded to the next step, planning their pregnancies with their spouse. Some of the women (3 out of 8) had unplanned pregnancies, two of which were unwanted.

An unexpected finding was that the majority of the women (5 out of 8) identified and experienced what they considered to be *key events* during pre-conception and discovery stages of pregnancy. Such events loomed large for most of the women during these early stages of pregnancy.

Findings related to emotional support revealed that the majority of women (7 out of 8) experienced support from family members (parents, siblings, and children). Some of the women (3 out of 8) did not feel supported by their spouse during the discovery stage of their pregnancy. Four out of the eight women explicitly cited the workplace as a source of support.

In the presentation and discussion of findings, the women speak for themselves, revealing those experiences they deem important in relation to the stages mentioned above. In this first chapter, the researcher introduces the reader to each woman at the beginning of their pregnancy

story, by providing some identifying details prior to the women's first quotes.

The women did not appear to have trouble in returning to and recalling this beginning period of their pregnancy. They conveyed this part of their pregnancy story with clearness and thoughtfulness, often revealing a range of emotions as they recalled the events. The following is a discussion of the findings with explanations and expanded details that support each finding:

The Decision

An unexpected finding, which surfaced during this study, was a step prior to the joint pregnancy planning between the woman and her spouse, which included a personal decision by the woman to have, or not to have a baby, and the presence of factors, which influenced this decision. There is little research on this subject, except in relation to adoption. For example, Curtis (2004) found that social workers providing counseling around adoption believed that the decision to keep or relinquish a baby is largely dependent on the birth mother's emotional capacity to tolerate the loss of the child. Curtis (2004) hypothesized that such a decision may be more related to social workers' influence. In this study, the decision was in relation to child- birth, not adoption, but Curtis' suspicion of other influencing factors at work in relation to the decision is evidenced in this study.

The majority of the women (6 out of 8) made a personal decision about childbirth prior to joint pregnancy planning with their spouse.

Such decisions occurred, in some instances, long before the woman and her spouse jointly discussed the timing and planning of the pregnancy. However, the personal decision to have a child did not always match the realities on the ground. That is, powerful influences seemed to have been at work that overruled more rationale or practical reasons for not having a baby. Conversely, a woman may decide for a host of reasons not to have a baby. In either case, the mother's decision, at this point, may set the stage for problematic issues and tension that could affect the entire pregnancy, as necessary emotional and practical adjustments are made to have the decision fit into her family's reality.

The researcher first became aware of this step in the planning process when Yvonne, mother of 2, described her "unexplainable", and apparent unstoppable desire to have another child, which seemed discordant with the description of factors, which comprised the larger context of her life during this period. It became apparent that there were other pressures, which influenced her decision about having another baby prior to joint pregnancy planning with her husband despite the existence of opposing factors.

The following accounts of the pre-pregnancy decision process reveal an important distinction between a woman's personal decision to have, or not to have a baby, and what the literature refers to as a *planned pregnancy*, which in this study assumes involvement of spouse.

It should also be noted that of the 6 women who made a personal decision about child-birth, one made a decision not to have a baby. None of the 6 had experienced a prior unexpected loss, and 4 out of the 6 had prior successful birth outcomes.

The findings reveal a range of reasons for the women's personal decision around childbirth and begin with Yvonne's account:

Reasons for Decision Recalled:

Self-Imposed Pressure

Yvonne is a thirty-three year old early childhood specialist, and mother of two boys (ages 2 and 4). She was interviewed in her new single-family home, in a suburb of NJ, while both children were outside the home with childcare professionals. Her husband, Kevin, an engineer, was at work. Yvonne was home recovering from a torn ligament in her foot which, as she pointed out, was the same time she would have been on maternity leave with her new infant.

Yvonne shared feeling worried about raising another child on her work and finances but especially on her energy level. Nevertheless, she talked about her "unexplainable" desire to have three children:

Umm I felt like, my body needs a rest but, I gotta go get the kids, I gotta go pick them up, or I gotta go cook dinner, or I gotta go to work, or yeah... So you take a little breather and then you get up and you do what you need to.

Despite this daily fatigue, Yvonne found herself still yearning for a third child. She explained that she lost her twin brother at birth:

We were supposed to be a family of five, but were only a family of four. I often wonder what that would have been like to have another sibling; to grow up with two other siblings. I just always wanted three children. I can't explain it.

Husband's First Biological Child

April age thirty, mother of three (ages 2, 4, and 8), and a counselor for high-risk teenagers spoke about her career as a dancer at length prior to working as a counselor. She married Charles a little more than 2 years prior to this pregnancy. Charles owns a courier business, and this birth would have been his first biological child. April's prior pregnancies were all full-term without complications.

April was interviewed in the privacy of her office in Manhattan, NY. When sharing thoughts around her personal decision to have a baby April focused on Charles's family history. Her decision to have a baby seemed tightly linked to wanting to give her husband his first biological child; a pressure she apparently placed on herself. She described the special significance having a baby would have for her husband, but never included any statements by him on the subject:

Yes, I wanted, we wanted to have baby. Charles (spouse) had no children and he was adopted, and his parents were old and they had been deceased now, so this was really exciting for him. He had a previous marriage and she had children but they

knew the dad, so having a baby now was really his first biological child. So it was a big deal for him.

Family Pressure

Dorothy a thirty-two year old OB/GYN physician had no prior births, and one subsequent birth. Her husband, Derrick, also a physician, was out of the country due to immigration laws, during her entire pregnancy, and during the time of their loss. Dorothy was interviewed in her home, located in a suburb of New Jersey.

Dorothy expressed ambivalence about her decision to have a child, but yielded to family pressure, “I knew they were waiting.” Both her parents and her husband’s West African family wanted the couple to have a family despite the demands of their respective jobs, and his immigration status. She explained the pressure she felt from her family:

Cause you know part of their culture is you know, be fruitful, multiply you know. I mean his mom was like finally what took you guys so long, because we had been married for like three years so you know. I knew they were waiting. And my parents are both older, so I don’t think my mother had retired yet, but you know shortly thereafter, and she was looking for something to do (taking care of grandchildren).

Biological Clock

Linda, age 34, an administrator in the area of social service, and her husband, Jim, is a manager in the airline industry. They are the parents

of a three-year-old boy, who was a full-term baby and born without complications. Linda was interviewed in her home in a suburb of New Jersey.

Linda had decided to have a second child, because she feared at that age of 34 her biological clock was running out of time:

Jim, (husband) often says that I made the decision to have two children long before he knew anything about it. He was right. My clock was ticking. I wanted to have a baby, and did not want the gap between my two children to be a big one. For my husband, it really didn't matter, but I wanted to have another child.

Fertility Worries

Freddie, a thirty one year old, had no prior children. She worked as a manager in the transportation industry. Her husband, Eric, works as a manager in the same field. They recently purchased a single family home where the interview took place, in NJ.

Freddie secretly worried about her ability to conceive. Her decision to have a baby was not occurring on her time schedule. Her constant use of first person, suggests that she made this decision prior to joint planning with her spouse.

I knew I wanted a baby and became worried that it was taking so long.

I was relieved. I thought there might be some fertility issues. I was feeling guilty. I wondered if I was having problems because I had an abortion several years ago.

Spousal Abuse

Alana, age thirty, had just completed her Masters Degree prior to this pregnancy, and worked as a counselor. She had two children (ages 3 and 4), both born without complications. Phil, her husband was physically and mentally abusive to Alana “on and off” throughout the 10 years of their marriage. Alana is now living in Atlanta, Georgia, therefore this interview, and subsequent contacts took place via telephone.

Alana was the only woman who made a decision not to have any more children, due to an abusive relationship. When she learned that she was pregnant, she also made a personal decision to terminate the pregnancy prior to sharing her pregnancy with her spouse; he agreed with her plan to terminate.

We were supposed to be trying (working on the relationship), but I did not want to get pregnant again. It was like your typical abusive relationship, umm breaking up, getting back together, breaking up, getting back together. And I did not understand myself then...just being stuck in that place.

She continues to explain and she and her husband could not carry out the decision to terminate when they discovered she was carrying twins:

I went to have an abortion. I didn't want to be pregnant.....Umm, two (twins) was too much, one was bad enough by itself, but two...I, I couldn't (terminate).

Planned Pregnancies

A planned pregnancy, as mentioned, assumes involvement with spouse. Research informs us of the importance of a planned pregnancy as it fosters co-existing behaviors attached to promoting a healthy pregnancy (Kost, et.,al. 1998). Most of the women in this study (5 out of 8) had conversations around pregnancy planning with their spouse. What was revealed in this study was that once a mother decided to have a baby, the joint planning followed. That is, the woman moved from a personal decision about having a baby to an open discussion with her spouse.

An unexpected finding is that 3 out of the 5 women (Yvonne, Dorothy and Freddie) who had planned pregnancies never shared feelings of ambivalence, fears and the pressures, with their spouse or others, during the joint pregnancy planning phase, nor later. The existence of secrets and how they play out in the pregnancy experience, is an area for further exploration.

Joint Pregnancy Planning Remembered:

Yvonne's 'unexplained' desire to have a third child overruled the "struggle" and concerns shared during the planning. She did not express her motivation to have a third child as an "unexplainable desire" to her husband, but rather placed it in the context of planning for another baby.

We struggled with the decision to have the third, as I said before, umm trying to figure out whether it was the best for us, for our two kids that we have now...umm and this little baby that would be here, and we decided yes with all the deficits like the finances... time, was less than the joy of having the joy of having that third.

So when I found out, as soon as I, we planned it, so I knew when I was ovulating umm, we, I knew how many days it took to figure out whether I was pregnant, I got several tests took three of them.

Dorothy frequently used the word “wiseness” in her responses around the planning to have a baby. Although she was clearly ambivalent about her decision to have a baby, the planning proceeded:

It was a plan, and I’m not sure the “wiseness” of the planning at that point.

Dorothy continued to explain that after three years of post-training she was employed in a hospital-based practice. Her husband, Derrick, also a doctor from Africa, was in the US on an exchange visa. Due to the exchange visa he had to return to Africa for two years upon the completion of his training. Dorothy never discussed her feelings about the “wiseness” of planning a pregnancy during such uncertain times with her husband. She offered the following as her reasons for questioning her own ambivalence:

Derrick did not “have much luck finding a position that would quality him to stay here. And umm...so anyways like I said the “wiseness” of that in terms of getting pregnant you know I really didn’t, I

didn't have any pregnancies before. I didn't perceive that I would have any problems, so I thought it's not really a big deal, even though knowing that he's not in the country at that time. I mean I was fine with it. I didn't have any reason to be pessimistic at that point; I mean it's something we both wanted. You know the fact that he wasn't there at that time, in my mind wasn't an issue.

Freddie's response changed from speaking in the first person (i.e. "I" to "we") suggesting a shift from a personal decision to the joint planning. She never shared her feelings of guilt and fear about a prior pregnancy termination interfering with conception before this research:

We were both ready. Yes it was planned.

Linda and her spouse actively planned the pregnancy:

It did not come as a big surprise like the first one. Yes, I would have to say it was planned. We discussed the timing, and things were in place to more easily accommodate another child.

*Unplanned Pregnancies*³(wanted vs. unwanted):

³ Definitions of pregnancy intention vary. Often the terms "unplanned pregnancy" and "unintended pregnancy" are used interchangeably. While the two concepts are highly related, in the demographic literature on this topic the term "unintended" refers to a very specific subset of pregnancies: those that were either mistimed (wanted at some point in the future but not at the time of conception) or unwanted (no pregnancy was desired at any time). Unplanned pregnancies tend generally to be unintended, but a small fraction are not. In some cases, those experiencing a pregnancy may not have thought much about its timing or occurrence, or they may hold ambivalent feelings about it that preclude categorizing the pregnancy either as unwanted or mistimed (Johnson, 2005). In this study the unplanned pregnancies were unwanted, except for one exception where the researcher identifies the pregnancy as unplanned but probably wanted.

Three of the 8 women had unplanned pregnancies, and 2 of the 3 unplanned pregnancies were unwanted. Unwanted pregnancies are associated with less prenatal care and poor birth outcomes (Pagnini, 2000). Women with unwanted pregnancies are at least two times less likely to secure early prenatal care within first 6-8 weeks, than those who wanted their infants (Mayer, 1997; Berger, 2008). Women with unwanted pregnancies are also less likely to recognize that they were pregnant for the first six weeks, and are more likely to have a poor birth outcome. (Kost, et al.,1998).

Tina, whose pregnancy was unplanned and unwanted, did not recognize she was pregnant for the first six weeks and was seen for prenatal care late in her first trimester; consistent with the research. Alana, whose pregnancy was also unplanned and unwanted, as mentioned, made her first visit to the doctor with the intentions of terminating her pregnancy, prior to discovering she was having twins. Wileta, whose pregnancy was unplanned but probably wanted, sought prenatal care within 6-8 weeks.

Unplanned and Unwanted/Feelings Revealed:

Feeling Trapped

Tina, thirty-three year old mother of one, (age 3) worked as a professional for a mental health clinic, while her husband, Frank, worked

as an IT specialist. Tina's prior birth was full term without complications. Tina was interviewed in her apartment in New Jersey.

Tina described herself feeling "trapped" when she realized that she was pregnant. Although this study did not measure for depression, Tina shared her feelings of sadness, anger, loss of interest, hopelessness, apathy and constant fatigue prior to her pregnancy. Tina did not use the word "depression" (DSM-IV-TR, 2000),⁴ to describe her state of mind and may not have realized that she was depressed (Williams, 2008).

Tina:

I was not planning on having a baby.....
Actually, I think it was Frank (husband) who asked me 'when was the last time I had my period?' He thought I was (pregnant) before I even thought about it. You know we had a three year old and things were not that great with us. I was happy in one sense. I wanted my daughter to have a sister or brother, but I was feeling angry and trapped. I was considering having an abortion... I did not tell anyone. By the time I was seen by the doctor I was about 2 months pregnant.

I was so tired and sick most of the time, I really stopped socializing before I got pregnant, jut not interested umm I was in a real funk...and then pregnant.

⁴ Depression appears to be a risk factor in giving birth prematurely, and higher pre-pregnancy depressive mood among black women compared to white women may indirectly contribute to the greater odds of preterm birth found among black women (Thomas, J. 2009).

Feeling Devastated

As previously mentioned, due to an abusive relationship with her spouse, Alana made a decision to terminate her pregnancy. However, once she discovered that she was having twins she could not carry out the plan. She was initially quite upset but eventually decided to make adjustments:

When I knew I was pregnant, I was devastated. I had a sonogram, and my doctor said “do you know you are having twins?” I said ‘twins’ and she said “yeah, are you sure you want to do this?” She (doctor) showed me the screen, which she wasn’t supposed to do. This took a whole lot of adjusting, physically and mentally.

This kind of adjustment did not bode well for the outcome of the pregnancy. According to the Family Violence Prevention Fund report (2008), women experiencing abuse in the year prior and during pregnancy were 40-60% more likely than non-abused pregnant woman to report a host of medical problems including vaginal bleeding, high blood pressure and urinary tract infection, and were 37 percent more likely to deliver underweight infants who may not survive.

*Unplanned but Wanted:**Feelings Recalled:*

Wileta, a thirty-four year Executive Assistant with a Marketing Firm, and a mother of a teen-age boy, married to Clay, a Musical Director for a

large church, one year prior to her pregnancy. Wileta had no prior poor birth outcomes, but a pregnancy termination several years before to this birth. Wileta was interviewed in her apartment in Manhattan, NY.

It was not planned... But not umm, I wasn't necessarily surprised because we were talking about having a baby. We weren't necessarily trying, but we weren't necessarily preventing. I was happy....

Key Events

The majority of the women (5 out of 8) identified and experienced what they considered *key events* during this stage of their pregnancy. The key events identified by the majority of women in this chapter, although attached to stress, coincides with the pre-conception and discovery periods being discussed here, with probable lingering implications throughout the pregnancy, and on the pregnancy outcome (Sable, 2000). Extensive research demonstrates the link between stress and poor birth outcomes, and the findings here set the stage for the examination of sources and effects of stress, which will be discussed in chapter VI.

The women were asked to identify events that were of special significance during the pre-pregnancy and discovery stages, with no definition offered. In each instance, the responses contained difficult issues the women faced. For example, an absent husband, or the prospect of a big job promotion during the discovery stage of pregnancy, was presented as significant challenges. Both of these examples create

conditions that could negatively impact the entire pregnancy (Sable, 2000). Alana was the only women who referred to a positive key event, in addition to other negative events she described. A filmmaker, doing a documentary on dealing with illness and faith befriended Alana, as he documented her mother's serious illness. This relationship was viewed as a bright spot during her entire pregnancy, and its effect on how Alana copes with the loss of her twins will be explored and further discussed in a later chapter.

The women's intensity and feeling tone as they recalled these events suggests that they loomed large in the background.

Key Events Recalled:

Serious Illness

Alana who was already dealing with an abusive husband when she learned she was pregnant also faced the serious illness of her mother:

It was horrible. I was dealing with an abusive spouse, my mom was severely ill (brain aneurisms) and scheduled for an operation, and I was responsible for my brother, sister, and my son and my daughter while my mom was sick, and I was carrying twins.

In the midst of the difficult issues and events she faced, Alana embarked on a "special" friendship with an independent filmmaker who was working on a documentary in relation to *sustaining faith during crises*. Alana was first introduced to him during her mother's illness, and

he later included her loss as part of his documentary. The relationship served as a bright spot during a very difficult time for Alana. She stated:

Actually yeah, I just met not to long ago, maybe a year prior at the most. And I met him when my mother got sick, my mother had two brain aneurisms; and she met him in seminary school after her first surgery she went to seminary school, and she met him. And he has been around and a support to us, ever since. Yeah, he was terrific; he's a documentary filmmaker. And he actually did, he did a documentary on faith, and the ending stories where my mother's story was featured when she got sick.

He would pick me up and take me out to eat and shopping and things like that, and just talk.

Husband's Absence

As mentioned earlier, Dorothy had to deal with her husband's immigration and work status, which required him to travel back and forth to his home country, West Africa. He was away prior to learning about his wife's pregnancy. Dorothy explains the sequence of events:

This was very uncertain times. There was no exact date at that point for when Derrick [huband] would return (husband). And in fact umm, April was my scheduled due date. And he had... because we were married actually he had to file paperwork. But because of his exchange Visa he still had to go back to West Africa first, and so it took like a period of about eighteen months, for this whole immigration thing to take place. So he had an interview date in November, so we figured okay by the time he goes for the interview, he had gotten a job in Nigeria, tell the people there he's gonna leave blah, blah, blah. He'll be back by January, February and I'm not due to give birth till April, so that will be fine....But of course that all came undone, and he was gone before

I learned I was pregnant up until after the loss of our baby.

Relocation of Parents: Recalling the Loss

One important event recalled by both Yvonne and Linda was the move of their parents out of state. They both talked about this with sadness and disappointment.

Yvonne described herself as still “reeling” from the relocation of her parents to Georgia, as they had served as her primary helpers for her 2 and 4 year old boys. She added:

I was still reeling from my parents move to Georgia. They were always there to support us with the kids. I began to really feel their absence when I learned I was pregnant. I started missing them a lot.

Linda knew her mother was about to move and was disappointed:

You know my mother was also retiring and moving to another state. That really affected me. I knew she was not going to be around for the delivery. I always pictured my mother being right there when I had my children.

Important Job Promotion

Linda also wondered how her pregnancy would affect her application or her desire for what she viewed as a great job promotion:

I had also learned around the same time that I learned that I was pregnant that I was up for an important position. I really was not sure how my pregnancy was going to fit into this plan. I was not

sure if once folks knew I would still be considered a serious candidate. Here was a great opportunity but I was not sure I wanted it, but I did not want to be discounted because I was an expectant mother. I was not sure how I was going to handle the whole situation.

Death of a Loved One

Wileta suffered the death of her pastor who was like a family member:

My pastor died. I was very close to my pastor and he was sick when I learned I was pregnant, and he died right after the loss my baby. I remember attending the service the next day.

Emotional Support

Family support is a well-known protective factor in relation to infant mortality (Jackson, 2005). In this study 7 out of 8 of the women experienced emotional support from family members (parents, siblings, children), and despite distance had close family ties. Five out of the 8 experienced support from their spouse. The women's description of how their family members responded to the announcement of the pregnancy signals the presence or lack of emotional support during this early stage.

Family Responses Recalled:

The parents and in-laws of Yvonne and Dorothy expressed real excitement about the pregnancy.

Yvonne:

She (Mom) was very excited. She said I knew it, I knew you were. His family was also happy. I still wanted to wait a little while longer before telling folks at the job. Everyone was really happy.

Dorothy:

Mm hmm. I mean I think part of the cultural, you know he was happy his family was happy. My parents were also very happy.

April focused on the responses of her three children:

The children were excited. I come from...umm my mom has six children. And I grew up personally neighbors to a woman who had thirteen children, so we're use to large families and a lot of black children around. Umm for them I mean they were young still but I think the thought of them having someone else that they could oversee I think added to the excitement. Everyone was excited for us.

Freddie included her boss in her account:

Eric (husband) kept asking me, "Are you sure?" Everyone was happy for us. They knew that we wanted to have children. My mother and my boss were very supportive.

Tina was unsure if her husband's response was genuine:

Frank (spouse) was happy; at least that is what he said. I told my bother and my mother. They were also happy. I told my father after I went to see the doctor. My folks are not together.

Everyone thought that we were the perfect couple. They expected us to have kids and live happily ever after.

Alana's parents and her in-laws were not happy initially but soon supported her and her husband:

I called my mother and Phil called his mother.
(Pause) And umm, they weren't happy at first,
(Pause) but as the pregnancy progressed they were okay.

I remember being surrounded with family more than problems. And I think that's how I got through a lot of things because we've always, we are just always there for each other and it tends to make you forget the problems.

Lack of Spousal Emotional Support

Paternal involvement is also identified as a protective factor against low birth weight and infant mortality in much of the literature (Gaudino, 1999, Milligan, et al., 2002). However, the literature also reports that Black men feel uncertain about the role they should play in the pregnancy process, and few are aware of the problem of Black Infant Mortality in their communities (Quinn, 2008).

In this study 3 out of the 8 women did not feel supported by their spouse during the discovery stage of their pregnancy. Additionally, 2 of the 3 women who did not feel supported by their spouse, had unplanned pregnancies.

Lack of Spousal Emotional Support:

Feelings Remembered:

Alana recalled that although her husband agreed that they should not go through with the abortion he soon started to show neglect and emotional abuse:

With the twins during the pregnancy it was more mental abuse. Just not knowing what to expect. Financially, you know, it was hard. I could not depend on him, it just became very hard...

Linda was confused by her husband's behavior,

I also remember not feeling very supported by my husband. He seemed preoccupied a lot. He was really not behaving the same and I thought he was sick or something, or just scared about the added responsibilities.

Wileta's seemed baffled by her husband's response to her pregnancy:

I can't say I felt supported by my husband. He had a strange reaction to the news. He wasn't excited nor...was he like...he wasn't excited, he wasn't upset, he was like okay good. And that was it.

Emotional Support at the Workplace

Although there is much literature around pregnancy and the workplace which focuses on flex schedules, risk management issues and child-care services, there is little that reveals the workplace as a source of emotional support for the expectant mother. In this study the workplace emerged as a place where important relationships were formed and news of the pregnancy was shared and celebrated. Four of the 8 women explicitly shared accounts of the emotional support they received from their jobs:

Emotional Support at the Workplace Recalled

Wileta's recollection of her co-workers response to her pregnancy was very different to the response given (above) by her husband:

I also told the folks on my job, we are pretty close, and they were happy and very supportive.

Yvonne shared the news of her pregnancy with a co-worker who was a confidant at work:

I actually told one person at work, so that I could have someone if something went wrong, or I needed to just vent. Umm, I'd have someone to talk to. And you know, she helped me emotionally, she was very happy and thrilled cause she knew I wanted to have another child.

Freddie recalled the much needed support her boss provided during her difficult pregnancy:

My boss tried to relieve my concern with being extremely understanding. He told me not to worry about the job during this period, and to do my best and keep him posted. I probably would have lost my job if I worked under someone else.

Linda shared her pregnancy with her close friends at work as she struggled a in making a decision about a job promotion:

I had close friends on the job that I was able to confide in during this rough period. They were my trusted sounding boards and advisors.

Conclusion:

This chapter entered each woman's pregnancy story from the pre-conception to the discovery periods. The researcher explored the *meaning of pregnancy* for each woman and areas that made up the larger context in which the pregnancy was planned and conceived.

The themes relate to the woman's reasons for wanting to become pregnant, (her personal decision), planned vs. unplanned (wanted vs. unwanted), key events, and her emotional support system, along with the integration of the woman's feelings and attitudes during these important beginning periods.

The findings begin to uncover possible sources of stress, which could affect the physical and emotional adaptation to pregnancy. One such source of stress emerged from the first finding involving the woman's personal decision to have a baby, prior to planning jointly with her husband. This could be a source of tension and stress between the woman and her spouse, with negative consequences throughout the entire pregnancy, if the decision does not fit into the practical realities of her family's circumstances.

Another important finding involved key events. The majority of the women identified and experienced what they considered to be *key events* during pre-conception and discovery stages of pregnancy. Such events included death, serious illness of a loved one, an absence

spouse, and the relocation of parents out-of-state. For the women, such events loomed large during this critical time of pregnancy.

Several of the women experienced the lack of spousal emotional support. Some of the research demonstrates that spousal support is a protective factor against adverse birth outcomes; therefore this finding could be implicated in the poor birth outcomes of these women.

The next chapter moves with the woman as her pregnancy progresses and health and medical issues for her unborn fetus become the center of her concern.

CHAPTER FIVE

FACTORS ASSOCIATED WITH MEDICAL CARE IN THE PREGNANCY EXPERIENCE

In this chapter, we continue to follow the natural progression of the pregnancy as the women move to now adjusting their pregnancy. In the last chapter, the findings and discussion focused on thoughts, feelings, events, and circumstances revealing the larger context in which the infant was conceived; a backdrop to the entire pregnancy experience. Findings in this chapter are crucial to telling and understanding the pregnancy experience of each woman, as health and medical issues become the center of concern in caring for self the well-being of their unborn infant.

The related research question, which guided the exploration for this chapter- *are there factors or issues imbedded in the black middle-class female experience, related to health issues and medical interventions, which could help in understanding the adverse birth outcomes for this target group?*

Several themes surfaced as the women told their stories in relation to their feelings toward their doctors; their interactions with their doctors; their health concerns; unexpected health issues, family history, and, for some, the role of race in the delivery of services.

There is a significant amount of research on quality issues in the provision of medical care, and on the doctor /patient relationship, as such

factors implicated in the consistent health disparities between blacks and whites across the medical spectrum. Therefore, areas of exploration included focus on the role of race and the quality of doctor/patient relationship.

Eight major findings emerged in relation health and medical issues. One finding demonstrated that the majority of the women (6 out of 8) in this study selected their doctors based on race or gender.

Another finding revealed that the overwhelming majority (7 out of 8) of the participants in this study expressed having a positive relationship with their OB/GYN doctor. However, some of the women (3 out of 8) had negative experiences with physicians during emergency medical interventions, which they attributed to race.

An important finding was the persistent and similar medical symptoms that the most of the women experienced during their pregnancies, which began to reveal cracks in the quality of care issue, and also provided clues to pending problems. The overwhelming majority (7 out of 8) of the women reported experiencing similar medical symptoms at various times throughout their pregnancy, which were probably precursors to poor pregnancy outcomes - *warning signs*.

Five of the women reported doctor's responses to medical complaints to be minimal, but reassuring. Responses included statements such as, "each pregnancy is different," "everything is OK," or "all is fine," after checking for the heartbeat of the fetus. In only one case was a test

(amniocentesis) ordered in response to the woman's complaint. These findings are included in the women's descriptions of medical responses to warning signs.

An unexpected finding was the prominence of precipitating events. The majority of the women (6 out of 8) experienced a single event, which they felt was directly linked to the loss of their infant; in some cases occurring immediately prior to the loss; *precipitating causes*. This finding proved to have significant consequences on the birth outcome, and the women paid an emotional toll as they speculated on how their loss could have been avoided.

The issues of blame also emerged as a finding. The majority of women (5 out of 8), attached blame to themselves, their spouse, or their doctor in relation to infant loss.

Researcher was surprised to learn the extent to which the father's family history revealed a history of preterm births and infant deaths, as the majority of biological fathers (6 out of 8) in this study had a family history of infant loss.

The following is a discussion of the 8 major findings. The intent of the researcher is to document a wide range of personal accounts vividly told by the women, providing detailed and thick descriptions (Denzin, 200). The accounts are very personal, and sometimes expansive, so not to compromise the authenticity of the experiences. The women shared their stories with transparency, desiring to give accurate and revealing

accounts. The fullness of the experiences documented, along with other critical data, provides a sense of the women's coping style, their personalities, and their thoughts as they deal with a range of health and medical concerns. This gives the reader a better understanding of what the women were experiencing as their pregnancy stories unfold, and an opportunity for the reader to enter into this part of their pregnancy stories.

Doctor Selection Primarily Based on Race and Gender

All of the women had the flexibility and freedom of selecting from numerous doctors. There was no mention of restrictive insurance plans, or other limitations in relation to securing prenatal care and/or specialized care. The majority of the women (6 out of 8) in this study selected their doctors based on race or gender.

The thoughts behind the selection of a doctor provide some insight into participants' preference and possible expectations in relation to the quality of the communication; the foundation of the relationship. Cooper and Roter (2003), found that among black patients, the level of satisfaction with doctors was more often linked to being seen by a doctor of the same race. Such findings are reflected in this study, as half of the women seemed to view race as an important factor in increasing their chances of being satisfied as they entered into a patient/doctor relationship with selected doctors. This may also be a differentiating

factor in this target group, compared to poor black women with limited choices in relation to doctor selection, which is the group most studied in relation to BIM. The statements of the women in this study, “I went to her because she is black, but since she’s the top person it was very hard to get an appointment with her.” “I went to her because she is black.” “My new doctor was a black female, and she headed the practice,” “I preferred a black doctor,” clearly demonstrates the important role race played in doctor selection, but also reveals, in some instances, a sense of pride and comfort in knowing that a black female physician was the head the OB/GYN practice at a major hospital.

In some instances, where selection was based on race, due to the nature of the medical practice, the black physician did not always assume the exclusive medical care for the woman. In these instances, there were no complaints expressed and the favorable feelings toward the selected doctor were transferred to the assigned physician. This was probably a result of the black doctor being the leader of the practice, a fact that continued to foster an increase level of trust, along with by then having experiences with other doctors in the practice that were positive. The findings below begin with such instances:

Reasons for Doctor Selection Recalled

Yvonne and Freddie had similar experiences, both receiving care at an OB/GYN practice attached to a teaching hospital. Although they

both selected their doctors on the basis of race and gender, Yvonne was never seen by her (selected doctor). Because Yvonne had positive experience with other doctors in the practice, her original reason for doctor selection (race) was now less important as the result of the trust she had formed with a white male doctor who had delivered her last son. In Freddie's case, her doctor did not see her until the third appointment:

Yvonne

Well I'd heard about her, Dr. Moon, through a friend, who had problems, with you know, growths, fibroids and other problems. And she just said, she's very good and she's a woman, and she's a black woman and she really took care of, the mental needs and the medical needs. So I went to her because she is black, but since she's the top person it was very hard to get an appointment with her. So when I got pregnant, I had to see all of them (doctors). I think my first visit was with umm, not the doctor who delivered my baby but one of the doctors whom I had seen on a regular basis; they were all good doctors. I ended up with the doctor who delivered my last son.

Freddie:

The doctor I had been seeing ...we didn't have a relationship. My new doctor was a black female and headed the practice attached to the hospital. I wanted to be seen by a black female doctor.

Dorothy expressed not having to spend time in the "getting to know you phase."

Yes. I went to a woman who was a colleague of mine, who was also like a mentor of mine. I felt comfortable with her. I did not have to spend time in the getting to know you phase, she is a woman, and she is black. That would be important to me even if I did not know her.

Wileta was clear about her preference:

He was my doctor long before this pregnancy. He has a good reputation and I preferred a black doctor.

April and Linda (respectively) were more concerned with gender than race. In Linda's case her doctor was an Indian woman. April's insurance coverage allowed her to be seen by midwives, white and Hispanic women. She preferred what she perceived to be the "naturalness" of the approach.

April:

I choose two midwives who were part of...the insurance that I had at that time with Oxford, and I had this... I've always been called a 'nature person,' I've always been health conscious. I was nineteen, twenty when I had my first two so I didn't know anything about midwives except through family. So now I'm older and I'm acknowledging midwives and I can understand the naturalness of their approach. I decided on those doctors, under my plan, who happened to be midwives.

Linda had no prior history with her doctor:

She was recommended to me by my cousin. I was looking for a female doctor. I went to her because she was a woman. I was new to the area and was

hoping that she would continue to be my GYN doctor after the baby was born.

Some of the women (2 out of 8) had other priorities. Tina valued the history of the relationship she had with her doctor. “He had been my GYN doctor for years”.

Alana cited familiarity and proximity as reasons for selecting her doctor:

Umm, there was actually a hospital right across the street from where I lived. And my oldest was born there so I thought they were pretty good with the first pregnancy so I returned.

Positive Relationship with their OB/GYN Doctors

The majority of the women (7 out of 8) in this study reported having a positive relationship with their doctors, and was pleased with the care that their doctors provided. The researcher had a particular interest in the quality of the patient/doctor relationship, as much of the literature suggests that such a relationship, or lack of, is the most important factor in the perpetuation of disparities in the delivery of healthcare services on individual and systemic levels (Johnson, 2004; Williams, 2000).

Additionally, much of the research findings demonstrate the existence of differences in interventions based on race (Todd, Lee, Hoffman, 1994), while other research demonstrates that access to health care for blacks may be infused with institutional and interpersonal racism (Harrell, 2000; Williams and Rucker, 2002). The question of whether such findings would hold true in this study was of particular interest to this

researcher. The key question here was - would race remain a factor in the patient/doctor relationship, thereby affecting the quality of care, for this target group?

In this study, race did not emerge as an issue associated with poor medical care provided by the participants' OB/GYN, or as a factor impeding the patient/doctor communication, as a substantial amount of the recent research demonstrates. Race as a factor in the selection process for the women (4 out of 8 selected doctors based on race), appeared to mediate such research finding, which point to disparities in medical care based on race. In other words, the fact that the women in this study had the power, flexibility, and freedom to select their doctor based on what was important to them, appeared to decrease the strength of race as a perceived negative factor in the provision of medical services, and the quality of communication.

Of the 2 women who selected their OB/GYN doctors solely on the basis of gender, one woman, Linda, did not have a positive relationship with her doctor. Out of the 8 women, Linda was the only participant to express negative feelings toward her doctor.

The following are quotes that capture the feelings the women had toward their doctors

Positive Relationship with Doctors Recalled

Yvonne, who had the “unexplainable” desire to have a third child, secured her care from an OB/GYN practice associated with a major

Teaching Hospital. She explains why she gravitated toward one particular doctor:

I, umm, I... gravitated to this particular guy in the practice, who had delivered my last son. I felt, I was so glad I got the appointment with him, I asked for him, and they did give the appointment to me with him. Jon was a breech baby, at 37 weeks and him instead, of letting him remain breech and have to do a C section, and he turned him around in my belly. So I really, really felt an attachment to this man, cause he really consoled me, he guided me, he said it's up to you; these are the pros the cons. Umm and he said I'm probably the best in this practice ever, in this particular procedure. So he was very honest. And I felt confident with him, so I was very happy him as my OB.

Dorothy had a “good” relationship with her doctor, but was not sure if it served her well when it came to sharing some of her medical symptoms; she did not want to be viewed as a “complainer:”

I had a relationship with her, and I had high level of confidence in her as a doctor, but I am not sure if the fact that I knew her affected my decisions in what I shared. Umm, because I'm thinking that basically you don't want to be a complainer.

Alana was impressed with what she viewed as thorough care:

I was assigned an Indian female doctor. She was very nice, I was comfortable with her. I mean they (the practice) were so thorough. I had HIV tests done, blood test for STDs they were very thorough. I was pleased with my care.

April's account revealed special feelings toward her doctors:

Oh I loved them; I loved them immensely. Even after that I was still trying to figure out how to visit them. You know periodically over the years I get a card from them that says don't forget your pap test and I would cry, like oh my god I love them so much, and I really did we had a wonderful relationship. I saw them exclusively. We had an excellent relationship.

Freddie did not seem to mind that her initial visits were not with her doctor:

I did not see the doctor that was going to deliver my baby during the first visit, although I felt reassured by the doctor who did see me. It was in my second or third visit that I met her. I liked her.

Wileta's doctor had delivered her teen-age son.

My doctor delivered my son, and I had a good relationship with him. He was a white middle-aged male; I trusted his competence.

Linda was one of the 2 women who selected her doctor on the basis of gender. She was the only participant who expressed very different feelings toward her doctor:

She was recommended to me by my cousin...I don't believe that she ever used her. She was Indian woman who never looked at me when she asked me questions. I don't think she ever addressed me by my name. I didn't know if this was a cultural thing or something else. I felt she had made assumptions about who I was, and therefore did not need to get to know me.

Negative Experiences with Physicians during Emergency Medical Interventions Attributed to Race

The issue of race did emerge during the provision of medical services for some of the women in this study later in their pregnancy. Three of the women pointed to race as playing a role in the quality and sensitivity of care they received during specialized and/or emergency medical interventions. For two of the women there was no prior interaction or relationship with the physician providing the medical interventions.

In the framework of general health care, BIM is one of a substantial number of documented poor medical outcomes associated with race and ethnicity (Blanton, et al. 2000). Therefore, the researcher suspected that the issue of race would have emerged earlier in the women's experience with the health care system since, as mentioned, a large body of research has established that the patient's race and ethnicity influences physicians' beliefs about and expectations of patients (van Ryn, and Burke, 2000). However, for the women in this study the issue of race around the quality of care surfaced later on. In each instance the experience was somewhat overshadowed by an agonizing emotional and physical state, as the women were faced with the realization that it was likely that their babies were not going to survive.

Negative Experience with Physicians Attributed to Race

Dorothy, a doctor, was hospitalized as steps were taken to stop the premature birth of her baby. She describes her experience in detail as she tries to deal with feelings of not being respected as a physician, and feeling ignored as a patient, which she, in part, attributes to race:

I was now at St. Ann's, a high-risk patient. After I moved into this new room I started feeling like leaking...and I thought it was a little bit odd, so I'm thinking I broke my water. So I called the nurse I told her, you know I think I might have broken my water. So she...what happened? So I showed her, there's like a little puddle of water on the floor. She calls the resident, the resident comes in and does an ultrasound so he's like no you didn't break your water, your fluid is fine. So I'm like hmm...but...right. So you know, my father comes and you know he's talking, and I can't really concentrate because every time I laugh and every time I cough I feel leaking coming out. And so I'm like you know this doesn't make any sense to me... but what can I do? Because nobody is...I'm telling them that something is going on but they're on...but they don't think that anything's going on. And it's a very surreal feeling, because I'm the type of person...I'm very in-tune with my body so I know, I know when something is different.

So eventually, the nurses change shifts and a new nurse comes in, and my dad leaves. And she's like what's the matter you don't look happy, and I said I'm not! Every time I cough, every time I laugh, and now for some reason I'm having the hiccups...I never have hiccups but this particular day I'm having hiccups, hiccups, hiccups and every time I hiccup I feel this leaking. Every time I laugh, every time I cough I'm feeling this leaking. And I said you know the resident came...and he said my fluid is fine. So she looked at the pad and saw that it was soaking wet...and she said not to be gross, but I'm gonna smell it...and it smells like amniotic fluid. I said I know...you know, I know my body and I'm not urinating on myself. So she was like okay let me

call, let me call the doctor. So the same resident comes back, does another scan...now I don't have any fluid...so he's like oh well I guess you did rupture. So now he calls my doctor, and then he comes and he's like you know well you know...you're twenty-four weeks and three days so we gotta take out the stitch blah, blah, blah. People don't think that it makes a difference ...especially...people will pre-judge you. Yes, my doctor knew that I was a doctor but he didn't go and so okay announce to everybody this girl that is in room so-and-so and so-and-so is a physician, is actually an OBGYN, which is fine with me, because I'm not the type of person...I'm not looking for the red carpet to be rolled out. But there's also a certain expectation on my part, on how I expect to be treated and how I'm gonna be treated. So you know, when he comes in the room and he's like oh you know I'm gonna do an ultrasound and I'm like okay...but I don't know who you are, I know he's a resident cause I don't... he's not my doctor, but do I know his name, do I know what year resident he is, did he say hello I heard you have a problem you know I came...so I wasn't trying to let him, I wasn't trying to tell him okay you need to check me and see what's going on, I wasn't really trying to deal with him. He was Asian. I am sure race played a role in how he was dealing with me.

Freddie's medical ordeal was exasperated by feeling that she was poorly treated because of her race:

We were sitting in the ER for 2 hours. I had been given instructions to have ER call my MD's offices and we did that and assumed that they were taking care of that. By this time my husband was pacing, then yelling, then screaming for me to be seen. It was hell, the worst day of my life! Finally a doctor came in and asked some questions, and coldly told me that the baby had to be delivered. I was very upset and did not want this doctor to examine me. How could he say this without even examining me? By this time my mother had arrived and I felt better having her around.

We wrote to the hospital about our ordeal. I just don't feel that I would have been treated by that doctor, resident, whatever her was, that way if we were white.

Unlike the other women in the study, Linda did not have positive feelings toward her primary physician from the outset. She shared feeling detached from her doctor during her first appointment, and such feelings were validated by the manner in which she felt treated by her physician during her emergency delivery, and during the aftermath.

Linda:

Either she didn't assess the urgency of the problem when I called her to tell her that I was experiencing cramps, or she gave me her routine response. The way I was treated confirmed what I sensed from the beginning. I think it would have been different.. you know.. if I were not black. I always felt that she had drawn conclusions about who I was.

She instructed me to take milk of magnesia and to lay on my right side, which I found out later, was the worst thing I could have done. I did and woke up about 2.5 hours later to cramps that were more intense. I called her again. This time she told me to go to the ER. It only took a few minutes to get there and we were placed in a room and waited for about 30 minutes before being seen by a doctor.

Warning Signs: Probable Precursors to Poor Pregnancy Outcomes

As the women's pregnancy progressed, and following the initial prenatal care visit, the next communication with doctor was often in

relation to troublesome symptoms. The overwhelming majority of the women (7 out of 8) reported having one or two symptoms, throughout their pregnancy and, for most, were severe enough to consistently interfere with their daily activities. The majority of the women used words such as “severe,” or “much different from other pregnancies,” to emphasize the fact that what they were experiencing was in their view serious. In this discussion such medical symptoms are referred to as *warning signs*, which were probably precursors to infant loss.

The intensity and similarity of the warning signs are striking, which include spotting, lasting intermittently, extreme nausea and fatigue that, in some cases, lasted throughout the pregnancy. Of the 7 women who reported warning signs, several reported (3) having a “feeling” during the entire pregnancy that “something was wrong.” These 3 women all had prior successful pregnancies. Additionally, some of the women (3) stated that they had weight issues at conception and throughout their pregnancies, but were not given any special instructions by their doctors. Alana and Dorothy reported that they were at least 20 lbs overweight, while Freddie reported being 15-20 lbs underweight at the time of conception. The doctors’ lack of intervention may reflect findings revealed by Marshall & Janz (1990) research on doctors’ attitude toward prevention among 33 physicians. They concluded: “Black women who are seen early for prenatal care may face doctors who are ill prepared to hold

substantive conversations around behavior or other health-related changes to ensure a positive birth outcome.”

The women’s accounts include medical responses to their symptoms to provide a fuller description of the incidents. The initial medical responses for 5 of the women included checking the fetus’ heartbeat and offering reassurance that all was “fine” or “OK”. Only one test was ordered, an amniocentesis, for Welita, and Alana was the only woman whose doctor introduced significant changes to her daily routine during her 2nd trimester. Other more aggressive interventions were introduced only weeks prior to infant loss.

Warning Signs Remembered

Alana, who was carrying twins, described her pregnancy as “harder” and experienced severe morning sickness throughout the day. Alana was also 20 lbs overweight at the time of conception. She was placed on modified activity due to “carrying low,” during her 2nd trimester. It is also interesting to note that Alana did not reveal her abusive relationship with her husband to her doctor, “Because they never asked”.

I had morning sickness in the morning, the afternoon and at night. Physically it was harder, you can’t walk as far and you can’t stand as long, and the morning sickness was doubled. It was not like my other pregnancies. My sickness was severe and lasted much longer. I didn’t eat as I should have because I had no appetite during this period.

Medical Response

I went to the doctor two months after the appointment when I learned I was having twins and I was told to stop working because I had a low ...umm I was carrying low. I was at this point I think going in my second trimester. I was placed on restrictions. Umm, no lifting, not a lot of walking, not too much, umm, just limited activity because it was still early, but you know just told not to overdue what I was doing.

Yvonne not only experienced “bad nausea,” but also shared that she had a feeling from early into the pregnancy that “something was wrong:”

It was very bad. Now I...everybody says each pregnancy is different. Umm, I only have one pregnancy to compare, well two pregnancies, prior to this one to compare. And both of my pregnancies were bad nausea. This one felt, seemed different, so I just said okay this one’s different, but the nausea was severe never vomiting, but just severe nausea.

I can’t, I can’t put a word on it...You know, I said to my mom, you know I don’t feel right. Umm she said well you know each pregnancy is different, and just keep an eye on it. And you know it would be hard to talk to your doctor about something that you just have a feeling about.

Oh but when I had my second visit, they did the ultrasound, that baby’s heartbeat was so strong... And he also said ‘the baby looks smaller, so you just calculated wrong in terms of your cycle.’ So it’s already not growing as much as it should have been, but he said you know with that strong heartbeat you know everything is fine.

I don’t remember which week it was. It was sometime after that visit. I started spotting, I mean so small, probably didn’t want to phone call, but because I just wanted to make sure that they

knew(doctor), and that I wasn't in any danger, I called and I spoke to the nurse.

Medical Response:

She said (nurse) 'you know it's normal for some women ... as long as it doesn't persist,'

Yvonne's symptoms persist:

Several days lapse and I'm still spotting. Thursday evening, I was a little "crampy", and...had a little, yes, still very minimal spotting, little cramping, of course...I believe I, no I didn't call, I didn't call, because umm I did what they recommended that I do before...rest, elevate the legs, rest, drink plenty of water, and that's what I did. And the cramping stopped. So at my next visit I am not experiencing the symptoms and everything checks out OK. I feel relieved.

Several weeks pass and the cramping starts again, umm I continued to cramp it got worse and worse. I was spotting more but nothing really heavy and this was like early maybe nine o'clock in the morning.

Medical response:

So then I called the doctor and he said well I don't like, the spotting is okay, but I don't like the combination of the spotting and the cramping together... you should go to the emergency room.

Dorothy, a physician, attributed her symptoms to having to stand for long periods. It is interesting that she did not share the "feeling of pressure" she was experiencing with her physician, who was only made aware of the situation when she observed Dorothy holding her stomach up during a chance encounter:

Because we had to do a lot of surgeries I started to notice that when I would stand up for a long time I would feel...I would get a lot of discomfort. I just attributed it to standing up for a long period of time. I started to compensate by sitting down during surgeries, so I would have the stool there, so I would stand up, sit down, stand up, sit down, and stand up sit down. Just like a pressure type of feeling, particularly when I stood for a long time. But it happened more so in the O.R. not so, because working on labor and delivery it's not like you're constantly standing; you're sitting and you get up, then you're sitting and you get up. So I didn't have that kind of problem, but when you're standing in the O.R. for a long time, that's when I start to feel like you know pressure. So that's how I compensated; I compensated by sitting down from time to time. And...Umm, this was probably about four and a half months, so I was around seventeen or eighteen weeks when this started. I did not tell my doctor because I did not think it was anything other than tiredness from standing.

Dorothy's statement, "people put a lot of credence into the doctor," provides some insight into why she did not share her symptoms with her doctor:

Umm, because I'm thinking that basically you don't want to be a complainer, you've seen a hundred thousand women who come in and they're all it's this pain, it's that pain, it's whatever. And quite honestly I didn't perceive it, as a problem because I figured this is just how it is; I had never been pregnant before. And so I noticed that I was having this intermittent kind of problem...

I think that to a certain degree for various reasons people put a lot of credence into the doctor. Well the doctor said everything's fine so it must be fine, well the doctor said so, so it's...and in that happening that also gives them the ego to feel like, I said there's nothing wrong with you, so there's nothing wrong with you.

Medical Response

It was about seventeen, eighteen weeks, she (doctor) happened to be in the hospital and I had just come out of the operating room and I was holding up my stomach, because it just feels better when I hold up my stomach. And she's like what are you doing? And I said well I don't know it just feels better when I do that. And she's like well why? What do you mean it feels better, are you having a problem, are you having pain? I said no, every now and then I just feel a lot of pressure when I stand up for a long time. And she's like well do you have this, do you have that? And I'm like no; no I don't have any bleeding, no spotting, nothing. So she's like well I'm want you to go home and stay off your feet, I'm gonna get you an ultrasound. And I'm like I don't need to stay off my feet, I'm fine, I've been doing this it's not a big deal, so she insisted on that.. 'I want to play it on the safe'.

The medical response to Dorothy's warning signs eventually culminated in her being transferred to a high-risk physician and two different hospitals in an attempt to stop the infant's premature birth after being placed on bed rest for one week.

Dorothy's hospitalization:

So I went back a week later (after bed rest). Right, I'm like between nineteen and twenty weeks. So they put me on my head, I stayed in the hospital, they put me on all these medicines to relax the uterus and you know okay fine. I'm in the hospital. My cervix is getting shorter, and so the (high- risk?) doctor comes back again and says here are your options, take it out whatever happens, happens, we could try and put in another stitch, you could break you're water this and that could happen, blah, blah, blah. So now he... at that time I was admitted into a hospital that only had a certain level of nursery that would not be able to take care of...if I had a premature baby. So he transferred me to another hospital No this is in Hoboken.

Wileta, whose pregnancy was unplanned but probably wanted, knew “something was wrong” in her first trimester:

Wielta:

Not long after I confirmed that I was pregnant there were issues because I was spotting. I knew something was wrong. It was not anything like my first pregnancy.

Medical Response:

He (doctor) didn't sound concerned...but I remember that he wanted me to have an amniocentesis. The next visit, it was closer to my fifth month I was supposed to take this exam, because my spotting never stopped. He said well you need to go take this test.

As Wileta continues to explain why she did not take the medical exam, researcher speculates that her delay may be evidence of her anxiety and/or ambivalence, in relation to her pregnancy, which is consistent with her expressed feelings at the time of discovery, “We weren't necessarily trying, but we weren't necessarily preventing.”

Wileta

Umm no, I did not, because there was a miscommunication. I thought he was telling me when to go, and I was waiting for an appointment, but in actuality I was supposed to call myself and make the appointment, and I didn't; somehow we miscommunicated.

Freddie started spotting one month into her pregnancy and felt “very, very sick” throughout. She was also approximately 15 lbs underweight:

I was very, very sick. I could not hold anything down. Everyday I was sick. I would try remedies-including the Sea Bands; nothing worked. It seemed that I started getting sick shortly after I was pregnant, and it did not stop until a few days before the baby came. I started spotting one month into the pregnancy. I thought “Oh my God, what’s wrong.”

Medical Response

I went to the doctor immediately, and doctor said everything was OK and this sometimes happens [spotting]. I should not be concern as long as it is not heavy bleeding. He did all kinds of blood test, including HIV but everything came back negative. We heard the heartbeat of the baby and I felt better. The doctor advised me to take it easy, but everything was OK.

Tina also stated that “this pregnancy was not like the first,” and was worried about her ability to function:

I wasn’t even sure if I could continue to work. This pregnancy was not like the first. I was sick all of the time. Nausea, headaches, dizziness. This was not at all like my first pregnancy, I could only eat those things that didn’t turn my stomach and it was beginning to feel like everything was making me ill. I started spotting around the fifth month and immediately went in to see my doctor.

Medical Response

Yes. He took tests and examined me. I have a good doctor and whenever I called or needed to see him he was always there. He reassured me that this pregnancy was “different”. All the tests were negative

He asked me if I was under stress. At that point I was actually feeling less stress than I felt when I first knew I was pregnant. He told me to take it

easy; this was not uncommon (spotting). He prescribed vitamins.

Linda had a “nagging feeling” that something was wrong. She was also being followed by a hematologist:

I did not have any concerns for the first three months, but later I felt very tired all of the time and just different. I had a nagging feeling that I tried to explain away as anxiety. It is hard to put into words, but I just felt that something was wrong. For one thing, after my third month I had to inform the job because I had expanded so quickly. I really could not understand how I was going to make it to nine months, I was getting so big.

Medical Response

Everything was always “fine” even when she referred me to the hematologist to “keep an eye on my clotting factor.” He (the specialist) assured me that everything was all right. I was scheduled to see him monthly for monitoring. That scared me, but he kept saying that everything looked fine.

Precipitating Causes Associated with Infant Loss

Six out of the 8 women reported what this researcher has labeled *precipitating causes* associated with infant loss. The strength of this finding was unexpected. The *precipitating causes* were specific events linked to pregnancy loss by the women. Unlike warning signs, *precipitating causes* occurred once, and close to the time of infant loss, or sometimes immediately prior to infant loss, and were accompanied by severe pain, and extreme fatigue, which in some cases subsided. The

women did not always report these events, to their doctors but they recalled the events as pivotal to pregnancy loss.

There is little research that links a single precipitating event to preterm birth, except in cases of sudden injury to mother and unborn fetus. An exception is Misra's, et al., (1998) research, which examined the effects of physical activity on preterm birth. Findings demonstrate a positive link between excessive exercise and poor birth outcomes. For the 6 out of the 8 women in this study reporting precipitating causes, a majority (5) involved excessive physical activity, and several (3) also involved significant exposure to large public places, and some (2) involved air travel.

Precipitating Causes Recalled

Dorothy's precipitating event occurred about one week prior to being placed on bed rest for two weeks, which was followed by hospitalization as a high-risk patient. She did not share her experience (the horrible pain) with her doctor at the time of the event, as in her view it was a one-time occurrence, and the pain associated with the event did not return:

Umm prior to that, I would say maybe around my fifteenth week I had gone to New Orleans with my sister. She was going to a conference and I just wanted to take a few days off, so I just went with her. We have been to New Orleans several times. So while she was at the conference, I said well let me walk and do some stuff, and there was one particular day that I decided to walk from one particular end of, you know not Canal Street, one of those streets,

to the other end. But you know stopping along the way, doing this, doing that, and coming back I almost couldn't walk. I started getting this really severe pain. So I thought you know, you don't walk like this on a regular basis, so why did you just start doing that now, the pain was just like...like something I had never experienced in my life, it was so excruciating literally I couldn't walk. I literally had to walk a little bit and stop, and basically force myself to get back to the hotel. And I basically just thought I overdid it, because I didn't walk like that on a normal regular basis, so I took some Tylenol I laid down; the next day, completely gone, completely gone. So again I'm just thinking this is not a big deal. I did not tell my doctor about this episode.

Dorothy continues to reflect on the incident:

I mean I think that in the immediate aftermath you know you go through this phase thinking what I could have done differently, you know maybe if I had told her (doctor) about the pain incident lot earlier things would have changed. When I look back I think this was really the turning point.

Tina's emergency hospitalization occurred approximately 24 hours after her return from St. Louis. Her husband called the ambulance after Tina's collapsed.

She expressed concern about the airplane trip and the possible negative effects on her pregnancy.

Tina:

I had just returned from St. Louis the night before. The flight was bumpy, and I really was not feeling that great after landing in St. Lou. I remember telling my sister that I was not feeling well and I wondered if I should have taken a plane. I heard so much stuff about airplane travel during certain times in your pregnancy. Anyway, I didn't feel well for the entire three days. I went through the motions. I

was extremely tired and had no appetite. I remember that morning, after coming back I started feeling slight cramps and called my doctor. By the time he called me back I felt fine. I took it easy for the entire day and I did not have any cramps. I was getting ready for bed around 9:00 pm and it was 12:25 when I came to. There was a clock right in front of me on the wall in the hospital. I know that it took sometime for the ambulance to arrive and I think we were waiting on my doctor, I am not really sure. I don't know if this is a memory or what they told me.

Freddie was told by her doctor to go to the ER due to cramps experienced 12 hours after an exhausting day which also included the night shift at work:

The day the baby came, I went to a baseball game, because I had out of town guests and we were all hanging out. I did a lot of walking. I believe I overdid it. During the game I was fine, but my back was hurting a lot. After the game I went to work (work nights) my back was still hurting much more severe now and I was extremely tired. When I got home I was cramping and I took extra strength Tylenol. It felt like severe menstrual cramps. I called my doctor's office and was told to get to the ER immediately. I started to cry, I felt this was not right. The contractions would hit me- boom! Then stop. I was at this point six months pregnant.

In Alana's case, her precipitating event resulted in immediate hospitalization. She describes the event and the subsequent medical interventions:

I was taking my vitamins and I'm doing good, I can get around I'm not doing to much but I can go to the store, and up the block and I was feeling fine until one day the elevator in my building broke and I lived on the eighth floor. I was twenty weeks pregnant at this point. I walked, with me feeling

fine; carrying twins I thought I was fine. Well if I take it slow I'll be okay, and I did the eight flights. So maybe later that night I started contracting and one of my family members took me to the hospital, and I was told that I was dilated half a centimeter so I would have to be hospitalized.

Alana shares her thoughts on what she feels happened:

Umm I think that walk up the stairs did it, because I was fine before that.

April begins sharing the event stating, "I'm feeling embarrassed slightly by it."

So we were involved, engaging (in sex), and my son busted in the door and was like, "Mommy!" So I jumped up and gasped, and when I laid back down I felt a sharp cramp like a piercing in my side, and I was like wow that's kinda strange and it didn't stop. So he got up and addressed the children, and I thought maybe when I jumped up I sprained a muscle. It kept getting a little more intense. I was in so much pain I could barely breathe.

Once I get the doctor, she tells me to come to her office immediately to be examined. Following the examinations she tells me to go straight to the hospital where the other midwife will meet me. She calls down to the doorman to be sure he secures a taxi for me. I remember entering the ER and being met by the other midwife. I remember her saying that an emergency procedure might be necessary and being placed on a gurney and pushed into what I thought was an examination room. I know that much more transpired, but it is fuzzy.

After the emergency procedure I learned that the baby was in severe distress and had shifted in such a way to cause immediate danger to me. She had to be delivered.

In seeking answers Yvonne reflected on a question she posed to her doctor, after the loss of her infant, about her emotional state, and linking an argument with her husband to her infant loss:

Yvonne:

And I asked him (doctor) if an argument, or me being extremely on edged could have caused this to happen. I asked him that because, you know when you're pregnant and you're hormonal and you're emotional and you may say things that cause arguments with your husband. I remember having this very, very heated argument with my husband. That was shortly before things happened (the loss). And I was saying to him you know why are you arguing with me? You know, you're not pregnant; you could cause me a lot of stress and cause me to have the baby now!

Umm, and to this day I don't remember what we were arguing about. But because I was so just emotional, maybe overwhelmed that day, I don't remember. Umm.. Yes. And it was so severe to me, because I remember feeling very, very umm stressed out.

The Issue of Blame

Blame as a theme surfaced as the majority of women (5) reflected on the events that unexpectedly seemed to change their birth outcome. They each posed questions as to whether their pregnancy outcomes would have turned out differently if they had taken different actions. For some there was anger attached to a genuine need to place their loss in a framework that provided some explanation; even at the risk of blaming themselves.

It is interesting that most of the women never discussed their reflections in relation to blame prior to this interview, except for Linda who blamed her doctor for bad medical advice. However, Linda later revealed, “feeling guilty” about her lack of wellness during her pregnancy, casting a degree of blame onto herself, and exposing a secret. Other secrets surfaced as some of the women (3 of the 5) discussed the issue of blame. Therefore, the finding here not only relate to blame, but also reveals secrets, which held by women in relation to their pregnancy loss.

Issue of Blame

For Yvonne the issue of blame was clearly attached to her husband. It first started with a tentative question to her doctor about a heated argument she had with her spouse. She blamed her husband for the argument, as revealed in her account under *precipitating causes*, where she states, “You could cause me a lot of stress and cause me to have the baby now!” Yvonne later reveals some of her other thoughts in relation to her husband’s medication for high blood pressure:

Umm, well one thought that I have had, I know they says there’s nothing that you can do, or have done. But I just wonder if there are things that you could do you know health wise. Naturally if you’re a person that has high blood pressure as many of us do, and are take high blood pressure pills on a regular basis.

Yvonne continues, as she explains why it is important to understand what happened:

It just seems like there has to be a reason that it happens, it just doesn't happen out of a vacuum. Why this infant didn't survive. (Pause) So I'm wondering if maybe there is something we can do, maybe to prevent this from happening again.

Dorothy's blame is more self-directed as she mulled over what could have happened if she had made a different decision about sharing the precipitating event with her doctor:

I thought about whether, you know maybe I should have talked to her (doctor) earlier in telling her about the pain, because I still don't know, you know I don't know if that had anything to do with it or not, in retrospect I wonder if that was the start of the problem, but I don't know, I mean there's no way to look back and know.

So, I don't know if you mentioned that some women know about having a relationship, [she is talking about the relationship with her doctor] I don't know if they think that maybe it's a problem, but I don't know if that worked in my favor or not.

I felt like a pressure type of feeling, particularly when I stood for a long time. But it happened more so in the O.R. not so, because working on labor and delivery it's not like you're constantly standing; you're sitting and you get up, then you're sitting and you get up. So I didn't have that kind of problem, but when you're standing in the O.R. for a long time, that's when I start to feel like you know a lot of pressure, so like I said I compensated by sitting down from time to time. And...: Umm, probably about four and a half months, so I around seventeen or eighteen weeks.

Right, and because people say... and this is why really people in the field of medicine people don't recommend that you take care of a family member, cause you can overcompensate or you could under compensate. You can think ahh well you know, Aunt Susie she's always a complainer so you could

minimize the complaint or I'm gonna do every test on Aunt Susie, even though she doesn't have any complaints. I mean I don't think that anything was held back or done extra for me in particular, umm and I didn't complain because honestly I didn't have any complaints, other than the time that...and I didn't come back running to her saying oh you can't you know.... And it's funny because I think about patients that have come to me saying you know two weeks ago I had this severe excruciating pain, what was that? And I'm like well number one it was two weeks ago so like how can I tell you what it was two weeks ago? I mean I could've called her, as soon as I came back I could've called her office and said you know I was walking a lot, and I had this excruciating pain. But, often as we are, which is creatures of human nature as we address it when it's a problem. So I didn't

Alana, Dorothy and Freddie used similar language in talking about what happened, "I overdid it," again suggesting that their actions resulted in the poor birth outcomes.

Additionally, Tina wondered:

If I should have taken a plane. I heard so much stuff about airplane travel during certain times in your pregnancy.

Linda blamed her doctor for giving her bad advice, but she also shared feelings of guilt about not taking better care of herself:

She instructed me to take milk of magnesia and to lay on my right side, which I found out later, was the worst thing I could have done
I stopped drinking socially. I don't think I made other changes. I forced myself to exercise a little. I did not pay close attention to **me** as I did during my first pregnancy. Throughout....I was feeling guilty

that I was not in the kind of shape I was in for my first pregnancy, so I was trying eat healthy. My husband and I use to work out together. After the birth of our son, I never seemed to have the energy or the time. Now I was feeling that this was partly the cause [of the loss].

Family History: Biological Fathers Linked to Infant Loss

Six of the eight biological fathers in this study had a family history of infant loss. This was a surprise finding, as much of the research demonstrates a link between maternal family history and infant loss. There is limited epidemiology research which links the father's age (older age) to increased preterm births (Astlofi, et al, 2006), but there is little research which implicates paternal family history to infant mortality.

The women recalled their own family histories and were aware of their husband's family histories in relation to pre-mature births and infant deaths. Some (3 of the 6) were somewhat surprised to learn about their husband's history after suffering their loss. There was an implication of guarded material with regard to the male's role in relation to infant loss. Yvonne described her husband's family as "secretive," and Dorothy states, "because of the way you know the culture is it's not something people necessarily talk about." What these accounts may be reflecting is the scarcity of information and research, and a necessary broader perspective in examining the biological father's role in BIM. Quinn, (2008) examined men's perceptions of Black Infant Mortality and found a

huge gap in what black men know on the subject, including how the father may impact the increase or reduction of the BIM rate.

Most of the women (6 out of 8) also shared a history of infant loss, which is consistent with much of the research (Varner & Esplin, 2005).

The below is a detailed account, provided by her mother on the birth of her brother, spontaneously shared by Dorothy:

Now so the other interesting thing is that, my mother actually had several pre-term births that I knew about but, I hadn't really...my mother had three kids me being the oldest, and then my immediate brother is about a year younger than me, and we knew he was premature. My mother being a lay person and not a medical person she would say she was about seven months at the time, at that time it was 1971 and they basically just told her go home forget about he's gonna die. And then at that time you know things were completely different, she wasn't allowed to go in and see him, you know she could see him from a window, but that was basically as close as they could get. And then three months later they gave her, her baby and said okay, you know, go home.

Two of the women could either not confirm their husband's history, as in April's case (husband was adopted), or had no reported spousal family history of pre-term births or infant deaths, as in Wileta's case.

Family History Recalled

Yvonne learned of a family secret from her father-in-law:

Yes. My husband's sister miscarried. She had three boys and I believe, at least what my husband has told me, she's miscarried two children.

After our loss, my husband's father who's very secretive, shared with us that he and his wife miscarried two children. My mom carried twins with me; she lost the other twin, and held me.

Dorothy did not learn about her husband's family history with infant mortality until his mother shared information while trying to console her.

Dorothy:

But you know again, because of the way you know the culture is it's not something people necessarily talk about. And so it wasn't until I had a problem, that Derek's mother, in trying to console me, was like well, so-and-so and so-and-so had you know...had this problem (speaking about her family members) and so that doesn't mean it's the end of the road for you, and this, that, the other.

Several of the women shared similar accounts, all being aware of their family histories and that of their husbands' family history in relation to birth outcomes at the time of reporting.

Alana:

My father's mother, when she was my age then, she had twins that didn't survive; and my last daughter came two weeks early and she was considered premature...she came out a month early actually she was supposed to come in April and she came in March. My husband's mother and sister had premature births, both resulting in deaths.

Freddie:

I know that my mother lost her first child. My mother-in-law also lost a baby, I am not sure if it was her first, or second.

Linda:

My mother lost an infant, and my husband's mother was a preemie, and her mother loss an infant. I didn't know anything about my husband's history until he brought it up one day, questioning it as a possible cause.

Although research demonstrates that a black woman with a previous Low-Birth delivery (LBW) is almost four times more likely to give birth to another LBW infant (the strongest variable linked to infant death) than a woman who had no history of LBW infant births (Rowley,1994; Varner & Esplin, 2005), such findings did not bear out in this study. None of the women reported having prior infant loss. Two of the eight women had terminations several years prior to their loss.

Conclusion:

This chapter presented findings, which emerged as the researcher explored those factors and issues imbedded in the pregnancy experience of the women in this study related to patient/doctor communication, health issues, and medical interventions, which might help to increase understanding and surface new material in relation to the adverse birth outcomes for this target population.

The primary finding is related to patient/physician relationship, which, according to the research literature, is a crucial factor in the delivery of medical care. In these instances race is recognized as the strongest

variable influencing the patient/doctor relationship and in the perpetuation of disparities in healthcare services (Blanton, et al. 2000). In this study, 4 out of the 8 women selected their doctors on the basis of race, indicating that race played a role as the women attempted to create the conditions for the best possible doctor/patient relationship. The women used phrases such as, “I went to her because she is black,” “I did not have to spend time in the getting to know you phase,” “She is a woman, and she is black,” and “I preferred a black doctor,” indicating the significant role race played in their expectation of a positive relationship with their doctor. In the end, not all the women who selected a black physician was seen by a black physician, yet the majority of the women (7 out of 8) had a positive relationship with their physician, suggesting that race was less important than the women expected. There may have been other factors at play, which allowed for an easy acceptance of their doctors, (i.e. power to choose their doctor based on preference, positive feelings toward doctor of choice, which transferred to other physicians in the same practice).

However, the issue of the doctor’s race did emerge during the delivery of emergency medical services. Three of the women who did not think they were treated well during their emergency hospitalization and attributed their poor treatment to their being black. Dorothy, a physician, felt that the doctor did not respect her as a colleague, and did not really listen to her complaints. “He was Asian, I am sure that race played a role

in how he was dealing with me”, Freddie was kept waiting in the ER for an inordinately long period of time before any doctor examined her thoroughly or showed any visible concern about what was happening. “We wrote to the hospital about our ordeal. I just don’t feel that I would have been treated that way by that doctor resident, what ever he was, if we were white;” In another case the doctor gave Linda bad advice, “I think it would have been different ...you know, if I were not black. I always felt that she [the doctor] had drawn conclusions about who I was.”

Warning signs played a perplexing role in the pregnancy experience for the overwhelming majority of the women (7 out of 8). The language the women used to describe these early signs of trouble were strikingly similar: “Not like other pregnancies,” “Severe morning sickness and nausea,” and “A feeling that something was wrong.” The women were actively concerned about these warning signs but when the routine tests suggested that everything was ok, the women experienced some temporary emotional relief. However, the women knew more about their bodies than the tests revealed. The tests turned out to be wrong in that they failed to pick up the existing problems. Is it possible that the birth outcome would have been different, if the doctors had listened to the women, or if the tests had produced positive results?

All of the women (6 out of 8) who reported precipitating causes linked them to their infant loss and in several cases blamed themselves and others. Dorothy who experienced her precipitating event in New Orleans,

but did not tell her doctor, wondered if her birth outcome would have been different if she had shared with her doctor what was happening at the time of the event. Tina blamed herself for taking an airplane trip to St Louis so late in her pregnancy, and Freddie felt that she “overdid it” by attending a baseball game and then going to work when she was six months pregnant. Yvonne wondered if a very emotional argument with her husband could have cause the premature birth ... “you could cause me a lot of stress and cause me to have the baby now!”

Another interesting and important finding was that the majority of the fathers (6 out of 7) had a family history of premature infant births and/or infant loss. Moreover, many of the women first learned of this family history only after their own loss. This information was secretive, as suggested by the manner in which the information surfaced. Dorothy attributed the somewhat guarded material to her husband’s culture, “you know the culture it’s not something people necessarily talk about.” Yvonne used the word “secretive” to describe how the information was treated by Kevin’s (spouse) family.

As the women shared the vivid accounts of their pregnancies it is clear that stress, stemming from managing the pressures of daily life, events surrounding their pregnancies, combined with difficult pregnancy experiences, is emerging as a major theme. It is also clear that medical intervention seemed lacking in effectiveness. The major themes from chapters IV and V provide the beginning trajectory of stress that began

from the time of conception and may well have been implicated in subsequent medical symptoms. Although the women did not initially explicitly identify such stress as a factor in the loss of their child, it is emerging as a major issue in relation to infant loss, combined with ineffective medical interventions.

In the next chapter, stress will be examined more specifically to gain an understanding on the women's perspective on stress, the sources of stress, and the coping mechanisms they employed in dealing with stress.

CHAPTER SIX

THE EXPERIENCES AND SOURCES OF STRESS DURING

PREGNANCY

In this chapter, the focus turned to factors impinging on the woman as she carried out her daily life activities and interactions while continuing to adjust to being pregnant. In chapter IV, the larger context of the pregnancy experience was presented from the beginning stages with potential sources of stress emerging (i.e. key events and lack of spousal support). In chapter V we followed the progression of the pregnancy, as the expectant mother turned her attention to health issues for herself and for the well-being of her baby. In this context findings related to medical and health issues were presented with the first probable outcomes of stress (warning signs) being evidenced. Additionally, race as a factor, in relation to doctor selection and in the provision of health care, also emerged.

The purpose of this chapter is gain a deeper understanding of the women's experience with stress, the sources of stress, her perspective on stress, and her coping behaviors related to stress. This broader perspective on stress is appropriate at this juncture as the findings in preceding chapters provided the beginning pathway of stress from the time of preplanning and discovery stages, and may have well been

implicated in subsequent medical symptoms. In this chapter, the findings are linked to the recognition, coping and sources of stress. The research question, which guided the exploration of areas in this chapter - *are there unique experiences with stress, which offer some understanding for the poor birth outcomes for this target group?*

It is important to offer a working definition of stress to provide a framework for the findings and discussions presented in this chapter: *Stress is a complex phenomenon that encompasses exposure to psychosocial, environmental, and physical changes and the body's responses to those experiences* (Sapolsky, 1998).

It should be noted that the body's response to stress, although measurable, may go unnoticed, or the sufferer may not attribute symptoms to stress (Cohen, 1983).

A number of themes emerged as the researcher sought to understand the women's perspective on the issue of stress and the role it played in their lives. The concept of self- expectation was one of the first themes to surface, and the descriptions provided by the women made references to a racial history and cultural framework in which this concept seemed rooted. In the examination of specific sources of stress, several themes surfaced which included: medical symptoms (warning signs), work/job issues, financial options, and problematic relationship issues with spouse and secrets.

Seven findings emerged as the researcher explored the women's perspective on stress and its source:

The majority of the women (5) expressed the influence of history, culture, and family on the development of their expectation of self, while connecting self-expectation to carrying out *business as usual* while pregnant. This is an important concept-*self-expectation*- and seemed to help shape the women's perspective on how she should behave while pregnant, and the way in which she perceived and coped with stress. The majority of the women (7) in this study recognized stress in their lives, but did not give it much value, or associate it with their adverse pregnancy outcomes. In relation to how the women coped with stress, 5 of the women shared ineffective coping behaviors in dealing with perceived stress. It is interesting that the coping behaviors seemed to either project superhuman abilities, and/or revealed a cautious approach to coping with stress (Herndl, 1995).

As the researcher explored specific sources of stress in the daily lives of the women, the first finding related to their medical symptoms, which played a significant role in their pregnancy stories. In chapter V stress was implicated in causing medical symptoms (warning signs), and here it is a source of stress.

A surprising finding was in relation to the women's job. Five women out of 7 (Alana was instructed to stop working after her third trimester) did not view their jobs as a source of stress. However, the majority of

women (6) expressed feelings of frustration, disappointment and vulnerability attached to the lack financial options, prohibiting time off during pregnancy, but especially after pregnancy.

Five of the women cited relationship problems with their spouse during their pregnancy, and for some, throughout their marriage.

Keeping secrets was another interesting finding and a source of stress (Pennebaker, 2003). Five of the women in this study reported having personal and important secrets associated with their pregnancy.

It is important to note that the findings of each chapter in relation to stress have a cumulative affect, as there are no factors, which dissipate as the pregnancy progresses. For example, the presence of a key event (i.e. mother's serious illness, absent spouse, death), or father's family history linked to poor birth outcomes, have a deleterious effect on the entire pregnancy. We should therefore assume that the findings on stress presented in this chapter have added consequences on the women's health and on the well-being of her fetus.

Below the discussion and findings on the broad area of stress in relation to the pregnancy experience, begins with the influence of history, culture and self-expectation.

The Influence of History, Culture, Family on Self-Expectation

Life stressors include situations that occur across all socio-demographic groups. However, for people of color, and for the women in

this study, there must be consideration given to the vast amount of research, which links stress to the “unique person-environment transactions involving race,” which is a different experience from their white counterparts (Thompson, 1996; Harrell, 2000; Smedley, et.al. 2003, Institute of Medicine, 2006). Additionally, African American women are confronted with the particular stressors that emerge from the simultaneous experiences of race and gender. The recognition of such factors provides a foundation on which all other stressors rest. In other words, black women start with a “stress glass” half-full.

It is therefore, not surprising that the majority of the women (5) in this study cited the influence of a racial history, culture, and family on their expectation of self. In many ways the words of the women in this section helps in understanding how they coped with and perceived the stress in their lives. It provides a context for the discussion of stress, which, shaped by history, culture, family, and race; evidenced in their own words.

The description below shared by Carla, a member of a focus group (a source of data from an unpublished research study on the same topic by this author, 2001) is used here to enter the presentation of findings for this chapter. Carla’s description encapsulates the experiences of the women in this study as they struggled to deal with stressors linked to history, family, daily responsibilities while maintaining their status. Carla’s description also reveals themes linked to self-expectation and

self-worth as she struggles to perform in a *business as usual* manner, while pregnant. The experience of racism, which Carla alludes to in her account, is not presented as an experience involving a direct affront, which is consistent with how some of the women in this study also raised the issue.

Self-Expectation: One Woman's Experience

Carla

Carla, a thirty-three year old Black-American female journalist, mother of 2, and at the time, her family's primary breadwinner. She spontaneously responded to the researcher's description of the study (same topic), sharing part of her pregnancy story as she attempted to negotiate her work and family responsibilities while being pregnant.

Carla worked daily on the afternoon and late evening News, and then rushed to catch the last train home, almost two hours away by car, always with little time to spare. She imparted what she described as an "awakening" on carrying out *business as usual*, to the group, while being almost eight months pregnant. On this particular Friday evening, her boss insisted that she work on a "special" assignment. What was always present in her thoughts was the reality that if she did not make it on time for her train it would mean having to spend a night at a hotel, alone.

Carla:

Ok, so it was Friday and I couldn't miss my train.
That happened several times before, and I was

determined not to miss my train. If I missed my train I would have to get up early enough to catch a train so that I could be home Saturday morning. We were trying to keep certain traditions going with my busy schedule, and I made a commitment to myself to make the traditional Saturday morning breakfast each week.

As I ran from the office I was angry, just feeling really pissed off, but I had to catch that train on time. “I had finally reached the platform and with a laptop in one hand, a briefcase and handbag in the other. I sped toward the doors, which were just about to close, and leaped inside the train like some crazed woman. I remember falling into my seat trying to catch my breath and thinking, ‘what in the hell did I just do!’ At that moment I decided that I was going to demand car service. Here I was working for the this network for almost five years, on the main NEWS twice a day and it had not occurred to me until then, at almost eight months pregnant, to ask for what should have been offered. I felt really stupid and angry. The thought to ask for car service just never occurred to me. If I were White, I probably would have kicked off my shoes (she is going through the motions as she is talking and places her bear feet on the end of the sofa, leaning back in her chair) and put my feet up, with an attitude of ‘ok, things are now going to be different around here, because I am not in my usual state,’ but instead I was just presenting the perky me until the baby dropped, and did not even think about it.”

Carla’s need to present herself as being able to conduct *business as usual*, “I was just presenting the perky me until the baby dropped,” regardless of the challenges posed by her pregnancy and her life’s circumstances, speaks to a level of self-expectation that is stressful to maintain, with real consequences. In Carla’s case, her delivery was by C-section, and several years later she succumbed to breast cancer.

April's description below continues the discussion:

Influence of History, Culture, Family on Self Expectation:

April's places her expectation of self in the context of her family's history and the role she played within her family.

April:

I grew up with a bunch of older woman, my mother's the only girl to her mom; she has...there are four of them and she's the eldest. For me the aunts I had were my mother's aunts, so I grew up with what I call ancient wisdom; with these older woman in the family and that's who I was around most of my growing life. My mom had to work so I was with them, I was there with them in their trench; learning from them, caring for them, being with them, you know I was the one in the family who learned this stuff. So in the family I'm the one now who does the things that my great aunt and my grandmother all of them are passed now, yeah I do; I'm the burden woman, I'm the one that everybody comes to, including my mother; when she's sick or has a cold, or they have a cut, or they need something created, I'm the seamstress, or (pause) whatever it takes. So it was completely normal to feel that with three children and a baby on the way that I could continue to work and do all the things that I normally do.

In the description below, Yvonne credits an "ingrained" history and her husband's minimal help to her ability to deal with adding another child to her family.

Yvonne:

So work was work, I think just the hustle and bustle of family life was just, a lot. Umm, honestly we do it because we have to, and as women, you know as black women we have ingrained in us that level of strength and tenacity. But without my husband (giggles), I don't know how I would do it because when I became pregnant, you know of course we have to give them a little nudge, and once you give them the nudge they fall in place and then they do they step up. So he would do the dishes, or do something that he wouldn't normally do that I would be responsible for doing, to ease some of the stress but it was a lot, you know with the nausea and just feeling bad, ill and then having to do everything else, it was a lot. So you take a little breather and then you get up and you do what you need to because it all has to get done, and I have to work. That's my reality.

Dorothy, who had a demanding job at a hospital as an OB/GYN, reveals an almost a stubbornness in yielding to the apparent physical challenges her pregnancy was causing, although she experienced “a pressure” as her fetus grew, which often required her to sit while operating, or hold her stomach up. She continued to perform her duties as if all was well:

You know I really didn't, I didn't have any pregnancies before. I didn't perceive that I had any problems, so I thought it's not really a big deal, even though knowing that Derrick was not in the country at that the time. I was living at home, at that time we were living in a house, in a townhouse. So you know I didn't have any maintenance, they took care of the grounds; they took care of the snow. So all I did was drive go, go out and come home. You know, most of my stressful interaction was just with umm, being at work, but I had that, wasn't necessarily unusual for me.

Yeah I definitely didn't attribute any particular problem to stress, or think that I had any problems at all; I thought that I was fine. Because I was working in a teaching hospital it was really not like I was operating by myself, it was more like supervising residents and so I could...which afforded me the opportunity to be able to sit down when I needed to, you know stuff like that.

Dorothy's continued her account adding influences of her family history:

I learned from my mother... who worked everyday...like now I tell people you don't even know what a sick day was. You had to be dead and if you weren't dead she was gonna kill you (laughs) you were going to school. She's from...she was born in New York and born and raised in New York. She is just like her mother who was also a very hard worker, you have to do it for yourself, you always have to be able to do it for yourself...so don't depend on anybody else.

Linda who was up for an important promotion did not want her pregnancy to be viewed as an impediment:

So for the first three months I just acted as though nothing had changed. I needed that time to figure things out. Hmm, I was beginning to feel real tired though, but just pushed myself on the job.

Nothing really changed at home. When I got home, I cooked and assumed responsibility for our three year old, and did all else as I would normally do. It was no different for other Black women who had to do the same. The celebration was over! I think with my first child the celebration lasted a little longer [laughter].

Freddie shared that she often thinks about her own mother:

Nothing changed I was working for a company that had a 24 hour operation. I started out on a part-time basis working nights and then became a manager. I continued to work nights because that is what I was used to. I was either sleeping or indoors during the daylight hours and this was the shift I've been on for years.

I was very close to my Mom, her oldest child, and she worked while pregnant, plus much, much more. It was rough for her. I think about her often... She was very strong, still is. Black women always had to struggle....but we are so strong. I planned to work, yeah; I just did not anticipate feeling so bad.

Recognizing Stress

The research is substantial on the risk of low birth weight and infant mortality if the mother experienced stress during her pregnancy (Wadhwa, 1996; Jackson, F. 2007; Malaspina, 2008). The recognition of stress and the role it plays in one's health, across the medical spectrum, has important implications in the reduction of stress, and in addressing the high infant mortality rates for Blacks (Harrell, 200). The majority of the women (7) in this study recognized stress during their pregnancy, but did not always articulate a connection between such stress and its impact on their pregnancy. The exception was Yvonne, who told her husband during an intense argument that "you could stress me out and cause a miscarriage." Research findings support her statement, which shows that women who are caregivers heal more slowly after a spousal argument. They tend to experience a prolonged stress response with physiological

consequences (Mercado, et al., 1996). For the other women there was an acceptance of stress, but a tendency to devalue its import.

The women were not aware of the disparity between black and white mortality rates, or the issues surrounding the BIM phenomenon prior to this study; except for Dorothy.

Recognizing Stress

Yvonne acknowledged that thinking about needing to prepare for her new born was adding to her “everyday stress.”

In terms of what may have been added to my everyday stress, probably just the preparation, the realistic preparation of the adding this life to our lives. Getting the guest room ready, umm financial paying for daycare and a babysitter, who am I gonna get to take care, cause I really want them to go to a daycare center as opposed to a homecare provider, and just the overall preparation and finances. Umm, and I tried not to think about it during the first trimester.

Alana goes through a list of stressors:

I was dealing with keeping twins, on restrictions, not being able to work, and in an abusive relationship with my husband. My mother was also severely ill at the time, and I was responsible for my brother, sister, and my son and my daughter while my mom was sick. My sister was around eight and my brother was around fourteen or fifteen.

It took some prompting for Wileta to recall the stress in relation to her son during her pregnancy:

We were married for about two years, my son was fourteen and I was working full-time. Everything was pretty much...I'm trying to remember but everything was pretty much normal. We were and are still working on two major projects; two albums. This took a lot of time, along with work.

Anthony (son) had school issues. His school issues were always stressful. This particular year it was very stressful because he was attending a private Catholic school, and he was being almost mistreated, so I was kind of at war with them also.

Dorothy interjected her prolonged experience with racism into her description in an interesting way. It was as if she were breaking her silence on a long-standing issue:

.....because that's just...you're used to being.. you haven't gotten here by not thinking that people are racist, or not thinking that people are prejudiced against you, not knowing that people have prejudged you. That's what you deal with, that's what you have dealt with every day of your life. But what I'm saying is that as a human being you're not thinking, oh I'm getting stressed out at this moment.

Linda recalls having a lot on her mind:

Looking back I think I had a lot on my mind. It was enough in dealing with my son and all the other things...it was an ah, really weird time.

Coping with Stress

Five of the women shared how they dealt with perceived stress. It is interesting that the need to be seen as a being able to handle all responsibilities, *business as usual*, despite being pregnant and feeling sick, in contrast to the words presented by several of the women, which conveyed a weaker stance: “I did not want to think about it,” “I could only let in little pieces at a time.” This may suggest that for some of the women the number of stressors exceeded their capacity to cope. It takes a great deal of cognitive and emotional energy to constantly respond to stressful events (Harrell, 2000).

Yvonne spoke about her attempts to “delay stress” which raises an interesting point. Stress is both experiential and anticipated, which means the anticipation of stressful events can produce the same physiological responses as the actual event. Therefore, her attempt to reduce stress was actually creating stress (Jackson, 2007).

Coping with Stress

Yvonne:

I tried to, I made a conscious effort to say okay I’ll deal with the happy things like getting the room ready, and telling everybody, but it still was there. You can’t put stress on hold.

I would drink hot tea frequently; the flavored teas, and peppermint tea, chamomile tea. I would drink tea at night to relax myself.

Alana preferred not to think about things:

I never stopped to look at all the things I was dealing with. If I had done that, I probably would not have functioned. I just took one day at a time.

It took some prompting for Wileta to recall the stress attached to her son's problems at school while revealing her coping style.

I can't say that it contributed [loss of infant] because I was so busy with other things; there was not much time to let things get me down. But I remember that was something that was also going on at that the time. He...Clay usually lets me handle the school stuff but the family in general, while we were fine we all...I remember the day after I lost the baby I remember going alone to the parent-teacher's night because there was serious stuff going on at school.

Dorothy talks about not seeing stress as stress:

You know I am also more informed about stress and its relationship to prematurity. And what sometimes we call stress, sometimes we're not looking at it as stress, sometimes me as the individual I'm not looking at it as stress because that's just who I am.

Linda admits to trying to select the amount of stress she will "let in."

Maybe I knew that I could not bear knowing some things at the time. I could only let in little pieces at a time.

Sources of Stress

There are considerable research studies which demonstrate measurable stress responses to pregnancy issues concerning the health of the baby and the delivery process (*warning signs*), and chronic life stress, which is the degree to which life situations are experienced as stressful (*problematic relationship with spouse; worries about finances; secrets*) (Giscombe, 2005; Pennebaker, 2003; Wadhwa, 1996; Neggers, 2004).

Other research studies link racism to poor health outcomes, most formidably represented in the Institute of Medicine Report, 2003. Stress can be a chronic experience indicating frequent and regular assaults (*spousal abuse*) or it might result from an acute episode (i.e. death, loss of job, divorce, etc)

There is also a ‘weathering effect’ theory which is observed after prolonged exposure to stress which ages the individual producing ill health. In the case of pregnant women research suggests that “weathering” produced by cumulative stressors before pregnancy results in poor birth outcomes, supporting the importance for women to recognize and control, to the extent possible, levels of stress (Geronimus, 1992).

Sources/Medical Symptoms

Fears and anxieties during a pregnancy, specifically those linked to the health of the baby, the labor and delivery process, triggers physiological changes in the body, which can cause adverse birth

outcomes(Wadhwa, 1996). This is an important research finding as most of the women in this study (6 out of 8) experienced severe medical symptoms (warning signs), which caused fear and anxiety. Warning signs, as discussed in chapter V, are medical symptoms that went unresolved, and were often severe and persistent in nature, and probable precursors to adverse birth outcomes. Several of the women used words such as “scared,” “worried” and shared a sense of something “not right” in relation to the medical symptoms they were experiencing.

In this section *warning signs* emerged as a source of stress, while in Chapter V, *warning signs* were viewed as the probable outcomes of stress; a dangerous cycle as both have adverse affect on birth outcome.

Medical Symptoms (warning signs): Source of stress

Linda was very anxious about the size of her pregnancy, along with her necessary monitoring by a hematologist:

For one thing, after my third month I had to inform the job because I had expanded so quickly. I really could not understand how I was going to make it to nine months, I was getting so big and I was carrying low.

Everything was always fine even when she [doctor] referred me to the hematologist to ‘keep an eye on my clotting factor.’ He (hematologist) assured me that everything was fine. I was scheduled to see him monthly for monitoring. That scared me.

Tina and Freddie were both “worried.”

Tina:

So when I was home I was in bed, because I was either too tired or too sick. I was worried about this because on some days I was not functioning and I had a three year old and a job.

Freddie:

I stayed very sick to my stomach from the very beginning. My doctor did all kinds of blood test, including HIV but everything came back negative. We heard the heartbeat of the baby and I felt better, but still worried.

For other women there was an overwhelming sense of anxiety, which triggers a stress reaction. Yvonne, for example, stated that from early in her pregnancy, she felt that “something was not right. It’s hard to talk to your doctor about something that you just have a feeling about.”

Wileta’s high anxiety was in anticipation of the delivery:

I always had mental issues concerning pregnancy because I was always...always umm... even with my first child the issues for me, carrying the baby was fine, but I always worked myself up when thinking about actual delivery. Constantly through my thought process it always took me to delivery, how it was going to happen. I never really processed, this is how I analyzed myself, I always had issues with the process of having a baby, cause that always took me there (delivery).

Work and Job Security

There is no debate over the changed terrain in relation to women sharing the role of breadwinner with their spouse, although black women

have a much longer history of sharing this role than their white counterparts due to disparities in employment opportunities and in pay between black and white men. According to the Bureau of Labor Statistics (2010) among African- Americans, the unemployment rate has risen since the start of the recession by 4.6 %. The current unemployment rates for blacks is 15.6% compared to 8.2 %for whites . In light of this current job climate, and the history of discrimination in the job market, the researcher expected the issue of job security to be a source of stress for the majority of women in this study. What emerged instead was a view of the job as a source of emotional support where friendships were strong, and a sense of worth affirmed.

As demonstrated in the descriptions below, the majority of the women in this study (6 out of 7) did not cite job security as an issue.

Additionally, the majority of the women in this study, (5 out of 7) did not view their job as a source of stress.

Feelings Related to Work and Stress

Yvonne recalled a “good year” at work:

Actually that year was a good year, because every other year we have this big conference, which was just January 20. So I didn't really have big, big events, I just had my regular events, so it wasn't that stressful.

Dorothy did not view her stress at work as “unusual.”

I was living at home, at that time we were living in a house, in a townhouse. So you know I didn't have any maintenance, they took care of the grounds, they took care of the snow. So all I did was drive go, go out and come home. You know, most of my stressful interaction was just with umm, being at work, but I had that, wasn't necessarily unusual for me. Nothing had really changed, except Derrick was not home.

Wileta stated:

My job has never been stressful, so that's never been an issue.

Freddie loved her work:

I loved my job, I loved the work I was doing. It only became stressful when I was too sick to function. I felt bad. My co-workers would have to fill in for me.

April was familiar with the job, making it less stressful:

I was working in an alternative high school so those hours were kind of set. I was very familiar with the, and the job wasn't a hard job; it wasn't any lifting or tugging. I sat down at that desk and I advised teenagers all day. So it was... job, and was OK with it. I liked working with the students. I didn't find the job stressful.

In contrast, Linda who enjoyed her work recalled that her job was a source of stress:

I loved my job which was stressful at times, because of the issues and deadlines I always faced. But I think it was especially stressful during this period because of the new wrinkles [promotion prospect and pregnancy]. At certain points I really felt I was

under the microscope. So many people seemed to be depending on me to aggressively go after the job.

It can be assumed that Tina's feelings about her job, "I was in a job I hated," produced stress.

As previously mentioned, Alana, was the only woman who did not continue to work at the instruction of her physician.

Lack of Financial Options: Source of Stress

In this study, the majority of the women (5) expressed feelings of frustration, uneasiness, disappointment with regard to their financial options. All of the women in this study had full-time professional jobs at the time of discovery, this did not add to their ability to take extended time off for childcare. In 2004, for every dollar of wealth held by the typical white family, the African-American family had only 12 cents. In 2007, it had exactly a dime. (Ehrenreich & Muhammad, 2009).⁵

For most of the women in this study, maintaining their current level of financial security was not possible without the income they generated, along with her spouse, There were no excess funds set aside to

⁵The longstanding racial "wealth gap" makes African Americans particularly vulnerable to poverty when job loss strikes. In 1998, the net worth of white households, on average, was \$100,700 higher than that of African Americans. By 2007, this gap had increased to \$142,600. The Survey of Consumer Finances, which is supported by the Federal Reserve Board, collects this data every three years—and every time it has been collected, the racial wealth gap has widened. To put it another way: In 2004, for every dollar of wealth held by the typical white family, the African-American family had only 12 cents. In 2007, it had exactly a dime. So when an African American breadwinner loses a job, there are usually no savings to fall back on, no well-heeled parents to hit up, no retirement accounts to raid (Ehrenreich & Muhammad, 2009)

accommodated extended time off, and this was a source of frustration as the women tried to balance work with motherhood, or anticipated motherhood. These frustrations exasperated by experiencing sickness throughout most of their pregnancies, at work, and for some feelings of vulnerability in relation to finances were “scary” due to relationship issues with their spouse. More often, there was a feeling of disappointment expressed about needing to work throughout the entire pregnancy, and not having the option to take extended time off after the anticipated birth of the baby.

Lack of Financial Options: Source of stress

Linda’s frustration was exasperated by the prospects of a job promotion:

I knew I needed to stay on, we needed 2 salaries, but how happy would I be knowing that I did not pursue the job, and I had to then work under someone else? Maybe if I also had the option of walking away, I would have felt differently; but I needed the job. I was just feeling uneasy about the whole thing.

Yvonne seemed a little disappointed in her husband’s inability to be the sole breadwinner:

Every baby, I didn’t want to go back to work. Well, well you know what it did and we had discussions about that. And of course the ultimate answer was no. I’m sorry honey but we’re not at the point where I can be the sole breadwinner, umm and still live here in New Jersey and still have the things we want to have.

So I just knew that I have to go back to work, you know it did bother me but again, it is what it is, that's our reality. Umm I just had to, I wanted to at least have as much time as possible, at home. Yes. Yes, and I looked forward to my summers off, that's what helped.

Tina's uncertainty about her marriage gave her even less options:

Yes I was worried about me taking care of me. I really was not making the kind of money to live independently with a baby and a three year old.

I couldn't leave my job, we needed both salaries. I was not happy about my job. I was looking into making a change, before everything unfolded. I did not feel supported by Frank at this time. I even started thinking about my options. It was a very unsettling time for me. Things felt up and down all of the time.

Freddie:

I could not stop working, we needed both jobs, especially now. We had new obligations, new house, and plans which required both salaries. There were times that I was not sure. I was feeling so sick and so tired, I wanted to stop working, but I couldn't.

Alana was placed on restricted activity and instructed to stop working. This created additional stress, as her husband's financial support was unpredictable.

I wasn't working soon after. I had to stop. I was told to stop (working). On top of everything else, this was rough financially. We needed both jobs. So it was, you know not knowing when he was going to come in, not knowing when he was gonna give me money for household expenses, you know worried about things like that. With the twins during this pregnancy it was more mental abuse.

Relationship Issues with Spouse

The majority of women (6) spoke of problematic issues in their relationship with their spouse, which we can assume was exasperated by the pregnancy (Hogan & Ferré, 2001), and was a source of significant stress, extending throughout their pregnancy, and for some, throughout their marriage.

In chapter IV paternal support as a protective factor against low infant weight and infant mortality, along with findings on the lack spousal support experienced by some of the women during the preconception and discovery stages, were discussed and presented (Gaudino, et al.1999; Reichman, 2006),. The descriptions below show a range of difficulties from communication issues, to infidelity and abuse. The women's accounts expose feelings of disappointment, confusion and anger.

Issues with Spouse: Source of Stress

Alana described the length of her abusive relationship with spouse:

At this point we were, I would say late in the relationship we had been together for a long time, and the abuse had started maybe the second year, and we're talking about being at the eighth year now or the seventh year of marriage.

Tina revealed feelings uncertainty and distrust:

Everyone thought that we were the perfect couple. They expected us to have kids and live happily ever after. I felt we put up that façade for the sake of the

family. I don't know if my husband thought or believed it, but I didn't. Most times I did not know what my husband thought. He was not a talker; he had another life going on. I was just going through the motions, not sure yet what I should do. He (husband) was fooling around and I didn't know if I wanted to work at the relationship anymore.

Linda reflects that perhaps she could not bear to face her husband's infidelity during her pregnancy but knew all along:

It was some time after that I found out that he was having an affair. I am not sure if that had crossed my mind during the pregnancy. Maybe it did, I don't know. Maybe I knew that I could not bear knowing that at the time.

In a previous chapter, Wileta described her husband's reaction to her pregnancy, "He umm, wasn't excited nor...he was like...he wasn't excited, he wasn't upset, he was like okay good. And that was it." She later shared that his communication style was a consistent source of frustration for her.

She stated:

He can be very laid back, too laid back. It gets frustrating. It is hard to get him to show emotions, and when he does, its sometimes confusing

April explains that issues with Charles (her husband) became evident after their loss, as she described him as becoming "disconnected" and

“short tempered.” However, it is suspected that problems existed in their relationship long before:

Yeah, it got really hard after that I think for him. When it came time to pick me up at the hospital or to visit me, he really didn't visit that much. It was okay umm, he came to visit and then it was okay I got to go see so-and-so about some business, or he would sit and watch the basketball game and we really didn't talk that much then. I was worried, because I'm wanting to hug and cuddle and he seemed distant, and he was like I don't want to hug you cause I don't want to hurt you; I don't want to touch your staples. And that was like the beginning, when it came time to pick me up from the hospital, I'm calling and he was not home, he'd spent the night out hanging with friends or somewhere else, and I'm asking 'what's going on?'

April continues to give her reasons for her husband's behavior:

What I learned in retrospect, you know once again being without parents he's used to older people, cause his parents were older people, who adopted him; so he spent the night going over his frustrations with one of the older gentlemen in the neighborhood whom he counted on when he was frustrated, or mad, or tempered, or whatever.

Yvonne shared that the weight of communication problems experienced throughout the marriage became heavier after the loss:

My husband is not the type of person to just open up and say okay let's talk, let's just let it all out. I have to be the initiator. And even when I'm the initiator it still isn't even to the extent that I need. Umm, of course he tries to make it all better, but it's just not the same as what I'm looking for. This has always been a problem for us.

Secrets as Sources of Stress

Five of the women in this study reported hiding personal and important personal information in relation to pregnancy. Pennebaker's (2003) extensive research on secrets demonstrates the link between hiding traumatic or important information connected one's personal life, to increased incidences of stress related diseases, influenza, and even cancer.

Secrets, as a theme surfaced at different points during the course of this research. The researcher first took notice of this issue when Yvonne, Dorothy and Freddie shared not ever discussing with their spouse, or anyone close to them, their feelings of ambivalence, fears and pressures experienced in relation to having a baby. Secrets surfaced again, when Alana shared with researcher that she did not tell her doctor about the abuse, "Because he did not ask." In subsequent contacts, researcher learned that Alana and her mother were the keepers of her secret in relation to Alana's abuse

Secrets Exposed: Source of stress

Alana's and her mother were the keepers of Alana's abusive relationship:

It was just crazy. I was too ashamed to let anyone know what was going on. I went through all kinds of changes to hide it. I was just crazy.

Tina and Freddie felt guilty about considering an abortion after the loss of their infants. Tina also shared living a lie for the sake of appearances:

Tina:

I felt we put up that façade for the sake of the family. I don't know if my husband thought or believed it, but I didn't. Most times I did not know what my husband thought.

I went to my doctor a couple weeks after. I was considering having an abortion. I felt terrible. You know I was thinking about what I thought of doing early on, and feeling like this was my punishment.

Freddie:

I had an abortion when I was... several years prior and I thought this was God's way of punishing me. Maybe I did something wrong. I was very hurt... why me.

Yvonne kept a secret about how she was feeling, "something was not right."

After I first mentioned how I was feeling to my Mom, I know I kept that worry to myself. I felt that something was not right, but the doctor kept telling me otherwise...until the end.

Conclusion:

The purpose of this chapter was to understand the women's experience with stress, the sources of their stress, and their perspective on stress, and its importance in their lives and on their pregnancies.

The complicated issue of self- expectation surfaced early in this part of the pregnancy story, and the researcher attempted to situate this concept in such a way to provide the context to the stress experience as revealed in the words of the women.

In turning to specific sources of stress, the first finding related to their medical symptoms. The majority of women (6) expressed feeling “worried,” “scared,” “anxious” about the medical symptoms, triggers for physiological stress reactions (Wadhwa, 1996).

The researcher was surprised to learn that the job was not a source of stress for the majority of women (6) in this study. In contrast, the job, in most cases, represented a place where they received gratification and where important relationships were formed. However, the majority of women (6) expressed feelings of frustration, disappointment and vulnerability attached to the lack financial options attached to extended time off.

Six of the women talked about relationship problems with their spouse during their pregnancy, and for some, throughout their marriage.

The prominence of *secrets* in the study was another interesting finding. A majority of the women (5) reported having personal and important secrets associated with their pregnancy.

The findings in this chapter continued to follow the pathway of stress from the time of preplanning to discovery. In each chapter, the link between pregnancy consequences and stress becomes stronger.

In the next chapter, VII, findings and discussion will focus on reflections on the circumstances surrounding infant loss, and the women's thoughts on why it happened. The aim is to explicate material helpful in understanding the adverse pregnancy outcomes as the women share the final part of their pregnancy story.

CHAPTER SEVEN
**REFLECTIONS ON INFANT LOSS, HEALING STRATEGIES,
AND SUBSEQUENT BIRTHS**

This research project opened with presenting findings related to the larger context in which the pregnancy began, from the pre-planning to the discovery stages. In this chapter, the findings relate to the larger context surrounding infant loss with a focus on events surrounding the occurrence, and thoughts on the reasons for pregnancy loss as told by the person who suffered the loss. Here the research question asks - *are there unique experiences, feelings, or thoughts, explicated by the participants' reflections on the occurrence of infant loss, which might add to understanding the adverse birth outcomes for the women in this study?*

In the first section of this chapter, all of the women present *reflections on loss*- full descriptions of the immediate events and the emergency hospitalization. These descriptions are not grouped by sub-categories, as it is important here not to interrupt the flow of the accounts shared. Their husbands' responses, if shared, and the medical explanations provided to the women on what happened by their doctors, are included to present a fuller picture.

The second section-*post-infant-loss*- is divided into two categories and presents findings in relation to the grief and healing process and subsequent pregnancies.

Ten findings emerged related to the women's reflections on infant loss, healing strategies, and subsequent births: The first finding was attached to feelings of disempowerment, uncovered by statements expressed by the women (i.e. "I really don't understand why it happened.") Four of the women in this study shared such feelings.

Another finding had to do with the quality of the doctor's explanations on *what happened*. Five of the doctors provided explanations with little substance as to the reasons for infant loss.

In this study, of course, all of the medical interventions tried, regardless of the level of expertise, timing and intensity, failed at stopping the premature births (Behman, 2007).

A surprising finding was that the majority of the women (6) still made no connection between the stress they experienced during pregnancy, and their poor birth outcome.

Four of the women were alone at the time of their emergency delivery.

Three of the women made reference to God or their spiritual beliefs when sharing their thoughts on why they lost their infants.

Four of the women who had subsequent pregnancies had full-term births without complications; although in Dorothy's case, much earlier medical interventions were applied successfully, in conjunction with noted changes in her life.

Another interesting finding is that of the 3 women who expressed feelings of disempowerment, none were part of the group of 4 women who had subsequent successful pregnancies.

Four of the women who had subsequent pregnancies also reported significant life changes, compared to the other 4 women who reported no changes in their lives.

In this study, of the 4 women who had successful subsequent pregnancies, 3 had engaged in some sought of counseling, or ceremony to help them go through their grieving process.

It is important to remind the reader that there were no pre-existing or medical issues reported by the majority of the women (7), except for Linda, followed by a hematologist throughout most of her pregnancy. Two of the women, Dorothy and Alana, were hospitalized for two to three weeks prior to the loss, as medical interventions were tried to stop preterm births.

The descriptions below vary in length, detail, and intensity. The women's *reflections* (what happened) are shared by each woman in its entirety and start below with Yvonne.

Reflection on Loss

Yvonne contacted her doctor to inform him that she is spotting and cramping. He instructed her to go to the hospital. She was in her 2nd trimester.

Yvonne:

And I was here with the kids by myself so I had to call my husband and by that point so much time had elapsed. I think if anymore time had passed I would have delivered the baby here at the house. He came back home, we dressed the kids went to the hospital; it was before I left this house that I was bleeding. So I knew right then and there that something was terribly wrong. So we went to the hospital. They told me to go put on my gown. I put on my gown. She said I'll be back to examine you, and I said well I have to go to the bathroom first. Went to the bathroom as I'm getting up I felt pressure, and I had my baby shortly after.

Meanwhile, I'm of course crying hysterically and my husband came hours later, because we had to find someone to take care of the kids...everybody's working...so my father-in-law came...so that was the horrible, horrible...

Cause my cervix wasn't closing so they just wanted to do a DNC just to make sure everything was out.

Response of Spouse:

On our way to the hospital, you know he was crying, and I had to be strong for him. And I said you know I'm gonna leave, you have to be with these kids, so you know get it together. Umm, but he was very, very umm, surprisingly distraught. And I say surprisingly because you know, as women we're carrying that baby so naturally we're going to be in distress. And you don't think that men, connect with the babies as your carrying them. He was definitely connected with this pregnancy and that baby. Umm, my Mom even told me that he cried with her on the phone.

Doctor's Explanation

Umm and he was very, very, very empathetic He was [doctor} very comforting. He was a man, part of the practice. Again, one that I didn't really

know very well, umm and he said that there's nothing that I could have done to cause, there's nothing I could have done to prevent it, it happens more than I think, I think the numbers were one out of four pregnancies, this was my third, it's not uncommon. It doesn't he mean, he said, it doesn't mean that the baby was necessarily...he said there was something wrong with it, but basically there's nothing that I could've done... S: Meaning, I didn't do anything physically to impact the loss of the baby...

Yvonne's thoughts on what happened

I've asked myself that question so many times. Umm honestly I think that this particular, something was wrong with it, something was developmentally wrong with it or I don't know. Something was wrong with my egg, or my husband's sperm that created this little guy who couldn't make it. Now why, the heart beating so strong it seems like he was thriving or she was thriving, I don't know, I don't know what went wrong. Cause I would think that if there was something wrong it, it wouldn't have even gotten that far. But you know, I'm not a doctor I don't know. But I do think something was wrong with it. Right. It just seems like there has to be a reason that it happens, it just doesn't happen out of a vacuum. Why this infant didn't survive. (Pause) So I'm wondering if maybe there is something we can do, maybe to prevent this from happening again.

Dorothy

Dorothy was referred to a high-risk doctor who sees her following a period of strict bed rest for one week. She has since been in 2 different hospitals for 3-4 weeks and was in her 24th week of pregnancy at the time of delivery:

So they took out the stitch, they started to induce me and almost a day later, the next day was

Christmas day. It looks like somehow...well either...well it had to be... because according to them the baby was initially with the head down when they tried to induce me. Then the next day when he came, the baby had turned to be in the breech position, and so he was like we can still do a vaginal deliver if you want but there's risk of what's called decapitation, because the head is usually bigger...so he was basically like do you want to have a C-section? I agreed to have a C-section...while crying. So that's when my son was born, December 25, 2006.

I mean I did think that I was okay. Umm, I my son...passed away in July, so that was just like...it was a relief it was a very mixed bag, because he had had so many surgeries, and ups and downs and different problems. So you know, on one hand you know want everything to be successful and for him to get better but you know, but at the same time with each set back and I think by five or six months I had had it. I was exhausted, and I was just like how much more can I you know really go through.

Response of Spouse:

Well, you know I think that...you know..well by now Tony had come back [after the birth, baby is in neonatal]. Again it was all crazy because in that time period of me going for this ultrasound and that ultrasound and being hospitalized, he'd gone for his immigration interview and he got approved and he could have left the next day. But you know I said well, because you can't go over there and say I'm only gonna be here for two years can you give me a job, I said just let them know what's going on, talk to them, just give them a reasonable time period and then you know try and get back over here. So he was gonna try and work through the end of the year, and January he was gonna come and blah, blah, blah. And for West Africans Christmas time is a very busy time of the year, a lot of West Africans are traveling to their homeland, because they have a lot of cultural celebrations. Once I delivered on Christmas day, it wasn't like he could just pick up and get on the flight the next day, so he had to...you know a lot

of things get closed down because of the Christian holidays and the Muslim holidays, it's not like here where you just pick up the phone and there's just somebody there 24 hours. It just doesn't work like that, which is difficult for a lot of people to understand. Umm for me because I had experienced it from going there, I knew you know there's nothing he could do. Umm, but he eventually did come in January, because that was the... he came like January 10 because that was the earliest flight his brother could get him on, to come back. Because a lot of people from here go to Nigeria for the holidays, and then they all come. It's just ridiculous. So that was the earliest time he could come back, so you know he was having his own issues because he wasn't here maybe if he had come back sooner, you know something, he could have done something. So whatever, that was a whole other thing. But Uhh...(sigh).

Doctor's Explanation

Well looking at it, at that point is that at the time when they were able...when I did go for that ultrasound the cervix was short so. It's called an incompetence cervix and the only problem at that point was that the process had already started...so...the doctor that helped to take care of me umm, he talked to my mother, one of the times that she happened to be in the hospital, and at the end of the whole thing he said you know there is some information about heredity and incompetent cervix and about six percent of people, it's not a well defined type of thing just tissue protoplasm strength blah, blah, blah, so he said that may have been a contributing factor. Which of course in the traditional way of training actually people don't really talk about that as being a significant factor for other women delivering pre-term? So it's not something that you really focus on, or is documented very well in literature.

Dorothy's thoughts on what happened:

Well I think if what the doctor is saying is true, in my case, umm that would be a contributing factor.

Because I can only look back now and think, was that when everything started? [She is referring to the pressure she was experiencing that required her to sit or hold her stomach up]. In my mind at that time I just attributed it to the normal wear and tear...yeah. And I think the episode in New Orleans was also.... in looking back there were things happening which I was not paying attention to, or just not giving value....

Well you know I think that before that time you interact with a lot of people...I interact with a lot of people...a lot of physicians. And I can very easily see how women are just hard-pressed to find somebody to really listen to them. It's a difficult situation because I understand it from the doctor's point of view and I also understand it from the patients point of view, but I certainly I...but an older physician also told me that sometimes you just have to listen to the patient you have to forget about defiance and you just have to listen to the patient.

I don't really know if it's going to help. But you can't teach...you know the problem with physicians is, most of us are coming into this as adults...very...you can teach people book knowledge but I can't teach you how to be a kind human being, how to be a nice human being. When you came out of medical school you either were or you weren't.

Alana

Alana shared what happened after walking up 8 flights of stairs (precipitating cause) and later, during the same evening, experienced contractions. She ended up in the emergency room where interventions began to stop her preterm birth; she was in her third trimester:

So I was hospitalized and they put me on all these different, I mean so many drugs to keep me from contracting. Yeah I was contracting on and off for the duration of the two weeks. At the end of the second week I started contracting, I was open a little

more, I prayed and said God I can't, it's up to you I'm ready. If it's gonna come let it come because I'm tired. And no exaggerations, no medicine they gave me worked I just kept contracting for two weeks

Their heartbeats [unborn twins] were still strong, and they were still moving. They rushed me up to the delivery room and just explained to me the twins' chance of survival, and they asked me if I wanted to resuscitate them. They asked if I wanted to have a specialist there, the pediatricians there and you know the team and I said of course. Cause either my choice was just let them come and you know, so I said no we can try. Something in my mind told me all the trying is not going to help. So anyway they took me and the doctor that did the delivery he took this object up and my cervix and made my water burst. And I mean a water bag for twins, oh my gosh water was just everywhere and I started pushing and I pushed out one, and I think he was stillborn, the first one and the second one came out and I think she breathed for approximately six minutes. You know they worked on her and she was breathing for like six minutes, and then they told me that she didn't make it. And they wrapped them up and they just brought them over to me.

Umm, my mother was there and my father, and the babies' father, and my aunt.

Doctor's explanation:

The weight of the babies, sometimes the uterus can't hold their weight especially after having other children. They made it seem like it's a type of, "it happens" thing; not like something was wrong or stress or you know nothing like that. It was more like sometimes your muscles can't hold that weight.

Alana's thoughts on what happened:

Umm I think that walk up the stairs did it, because I was fine before that. It's not my only thought, I'm really into my spirituality and I understand that things happen for a reason. They [twins] made a strong impression, they made a stronger impression

not being here than being here. (Sigh) Hold on one second. (Pause) Yeah, but they made a strong impression not being here. With the documentary and people coming to me and telling me their stories, they made an impression, that's how I feel about it; they did what they needed to do.

Wileta:

Wileta's description is the shortest, which is consistent with her style of communication throughout, and probably reflects a degree of unwillingness to relive this part of her pregnancy story. She was at the end of her 2nd trimester.

Umm...when it actually happened...I knew what was happening cause I knew that I was losing the baby, but when it actually happened it was very emotionally draining and I was quite devastated. I had called my doctor from my job (pause). I called my doctor and my husband from the job and I went straight to the hospital from there, so Clay [husband] wasn't with me. He was actually working when this was actually happening. He [doctor] told me to go straight to the hospital, when I told him what was going on [bleeding] because I had gone to work that day, and he told me to go straight there.

Response of spouse:

My husband he was very eager about it, very confident about it, very protective about it.

Doctor's response:

All he said was...next time I saw him he asked me how I was feeling, and gave me the statistics again, and said don't worry about it, this does happen and it doesn't mean you cannot have another baby. And that was really it.

Wileta's thoughts on what happened:

I don't really understand why it happened.
So...I don't think...something happened...I just
think the baby was not forming correctly and that
my body knew it.

Freddie

Freddie was told by her doctor to go to the emergency room after experiencing cramping. It was about 12 hours after a day of exhausting events, including work. She was at the beginning of her third trimester. Her quote continues from a prior description where she talked about her poor treatment, which she attributed to race (Chapter V):

.....that same doctor examines me and the pain is excruciating. I don't want him to touch me. A black female intern comes into the examining room and she sees that I am extremely upset and I between my tears share some of my story. She was the first person during that time that was responsive. She told me that she was going to find a doctor.

By this time Eric (husband) left the room to call my medical group. Now I am starting to bleed more. The blood is really red. Shortly after this I was taken down for an ultra sound. The lady performing this test said nothing. I could tell by her response that something was wrong. Eric was looking at the ultra sound and he said, 'Freddie. I think it is OK.'

By this time more than 5 hours lapsed and the intern now performed an internal examination. Right after that my water broke and gushed out—it was mostly cleared with a little red. My doctor finally appeared and clearly upset by all that had happened. She took over. She took over. "I need to do a D and C."

I've been there since 5:00 pm and it is now 10:30 pm. All I kept thinking was "What have I done to

deserve this!” The procedure was done and I remained in the recovery room for some time.

Response of spouse:

We were both so exhausted by the end of all this.... He was mad as hell. You know, the way things went. That was something to distract him from his grief. I know he was feeling terrible about the whole thing. He really did not want to immediately talk about it. We both needed rest.

Doctor's explanation:

She only said that sometimes these things happen and said I should be able to have children in the future. He was right [laughs].

Freddie's thoughts on what happened:

It is interesting that Freddie does not bring up the events of the day that precipitated the emergency delivery, even though she mentions it in a preceding section, under *precipitating causes*. She also talked about God punishing her under the section on *blame*; but here she tries to identify something physical as the possible cause:

Maybe it was something physical. I know that I have a tilted uterus. So does my mother. My doctor does not feel that this is a problem. I think I was also too thin...

Tina

Tina collapsed within 12 hours after returning from St. Louis. She was 6 months pregnant. She continues her description of what happened below:

Tina:

Shortly after I came to I started vomiting and having sharp pains, cramps. By then my doctor was there and examined me. He told me that I had dilated quite a bit and he would have to deliver the baby. He told me that my water broke, but I didn't feel when that happened. I was crying. I knew the baby was not going to survive. I was just in my sixth month.

They were trying to stop delivery, but I knew it wasn't going to work. I was crying. I knew the baby was not going to survive.

I felt terrible. You know I was thinking about what I, I thought of doing early on [abortion] and feeling like this was my punishment.

I really don't understand why it happened. I do know that the pregnancy was different and I often worried how I was going to make it through the full term if things did not change and there did not seem to be a change in sight. I just kept thinking about what I was considering earlier [abortion] on and felt really, really bad about that.

Response of spouse:

My husband was there and was really, really upset.

Doctor's explanation:

He said that there wasn't anything that I did wrong. He said sometimes it happens, and he told me the stats, which I do not remember.

Tina's thoughts on what happened:

I do believe that my trip had something to do with it; I mean things rapidly fell apart right after I got back. But I also think that the timing was not good. I mean there was a lot of internal stuff going on with me at the time. God has a way of working things out.

Linda

Linda called her doctor because she was experiencing cramps. She explains what happened after following her doctor's instructions to take milk of magnesia. She was 6 months pregnant.

Linda:

So I did what she instructed me to do and woke up about 2.5 hours later to cramps that were more intense. I called her again. This time she told me to go to the ER. It only took a few minutes to get there and we were placed in a room and waited for about 30 minutes before being seen by a doctor.

At this point I was six months pregnant and everyone was concern about the infant being able to survive outside of the womb so they attempted to stop premature labor.

I was scared. I started to cry uncontrollably. This nurse who was with me the whole time said, 'Linda. You must try to gain control of your emotions because it can really create more problems.' I really tried to pull myself together. I can hear her voice in my head now. It really gave me strength.

They waited for about 30 minutes before they examined me again. After that examination I felt my water break and the doctor explained that they would have to deliver the baby. He told my husband to put on a hospital gown and to follow us in now! We were not even in the section of the hospital where they normally deliver babies. It seemed like at the moment they wheeled me into that room the baby came out. The baby just gushed out and I felt my heart break. I was praying that maybe she would live. At that point my doctor arrived to clean me up, and to make her money. I could have done without her.

She was just too small and struggled for life for 7 days

Doctor's explanation:

She never expressed anything to me about my loss. To tell you the truth I wondered if she remembered me and the circumstances when I went to see her for a follow-up...maybe she felt bad about it and did not how to deal with it.
Ha, I don't see her anymore.

Linda's thoughts on what happened:

Looking back I think I had a lot on my mind. I also wonder if I was going to be able to physically carry the baby to term; feeling so terrible most of the time. I really don't know I don't understand what happened. I just felt burdened with a lot at the time.

April

April was examined by her mid-wife who instructed her to meet her colleague at the emergency room after coming in due to severe pain.

April is not clear about exactly what was happening, but feels the urgency. She is in her 2nd trimester. She explains:

I arrive at the ER and she is waiting for me [other mid-wife]. So they wheeled me in a small room where I am examined, and there's about four or five other people in there, and the doctor's like okay strap her IV up and do this for her, and so I'm like what's going on here? And the doctor's like okay great and they're again kind of like ignoring me... He finally tells me that they have to do an emergency procedure. He explains that the baby is in distress. He will talk with me after the procedure. Everything will be alright because they were going to take good care of me. He says that 'I should relax now we'll talk.' He asked me to start counting down from 99. That was the last think I remembered.

So I wake up in this room, and there's maybe other people around my bed, so from what I'm understanding it's an observation room and umm, I'm like okay why am I here? Someone comes to check on me and they're like how are you feeling? How's your pain? I'm like well I'm not in pain right now, but what's going on?

Later maybe hours later, I think I fell asleep and slept for I don't know how long, the doctor finally came around and said...and again I'm gone here, I really can't recall what he said. I don't remember anyone telling me I had an abdominal pregnancy, I don't remember anyone telling me I had surgery. I think somehow the conversation must have been wah-wah-wah-wah-wah, the end result was I figured out I didn't have a baby anymore but I couldn't hear it.

I don't remember in all honesty, I don't remember anyone saying to me, "We had to take the baby," because of any situation, I don't remember. So when I eventually got out and went to see the doctor, then she explained the baby somehow, don't know how, because we saw it in the womb, we saw it on the slides...how did it now get situated outside the wound?

Doctor's explanation:

We saw this baby forming; there shouldn't have been any problems or complications at all. I'm at her office for visits and we're looking at the child every time. I don't think that she (mid-wife) thought anything was wrong either. She tried to be comforting, but I could tell that this situation was upsetting to her.

Response of spouse:

The relationship became very strained afterwards. I was touchy, and sensitive, and accusing...anything. I don't know it just seemed like we had, before that I couldn't remember an argument, but then it's like we couldn't say the right things. There was no real good conversation without something of it becoming an argument for one or the other; someone seeing or

hearing something and taking it the wrong way. So it got a little hairy.

I think umm, I don't know all I can imagine now is that it was subconscious, cause I don't think we talked about me losing the baby...I'm sure, that's not a thought we never...we did not talk about that.

Our marriage ended less than a year after the death of the baby.

April's thoughts on what happened:

I think it was a result of my abrupt and extreme movement, which just caused something weird to happen, that rarely happens. Everything was really fine before that.

Post-Infant Loss

There is significant research (Price, 2008; Van, 2001; Morton, 1990) which focuses on what happens following the death of one's infant, which is extremely important, but does little to illuminate the possible reasons for infant loss. However, the pregnancy stories of the eight women in this study included themes, which emerged attached to the post- infant loss period, and linked to factors that may be useful in understanding poor-birth outcomes for this target group.

It was clear that most of the women were eager to share this information. Therefore, the material shared by the women, which covers the post-infant loss time period, is included here as part of the ending to their pregnancy experience. The major themes discussed below are coping with grief (healing strategies), subsequent pregnancies and the significant changes in their lives.

Coping with Grief: Healing Strategies

The grief responses are more reflective of healing strategies shared by each woman. An interesting finding in this study is the link between certain kinds of healing strategies to subsequent successful birth outcomes. Of the 4 women whom had successful subsequent births, 3 received counseling, or participated in ceremonies, which helped them to reach a sense of closure.

A number of healing strategies employed are reflected in their words and activities of the women and include: Taking Action; Ceremony as a Source of Healing; Moving On; Time as a Healer; and Delaying Action.

Healing Strategies

Taking Action

Dorothy was the only woman in this study who sought counseling sometime after the passing of her baby boy.

Umm fine, you know it's gotten better, you know in the beginning you know you don't talk about it, I was fine, I was completely fine. And I actually...did eventually get counseling but almost for like a year later, because around Mother's day like the next year or so, he passed away in July, so I was fine...and then I don't know it was either before or around Mother's day. And I just kept thinking Mother's day, Mother's day, Mother's day well am I a mother, am I not a mother...and I...Uhh.... Oh yeah, so I just couldn't go to work without crying, because I couldn't figure it out. So I did eventually get counseling, so that was very helpful. But you know I'm okay, I think I'm okay.

Ceremony as a Source of Healing

Alana was the only woman who talked about the burial ceremony for her infants. It is evident that the experience in being able to share her story with others, as she assisted in the making of the documentary, also proved to be a mediating factor in helping her cope with her loss and the suffering surrounding her during her pregnancy:

We had a burial for them, so I actually got closure. We had them cleaned and dressed and everything, and actually we had a casket we had made for them, and my mother has a picture of them.

I mentioned the documentary before. I mean for the most part he [researcher] just kept me busy working on the documentary after the babies were born.

Yeah, he was terrific; he's a documentary filmmaker. And he actually did, he did a documentary on faith when faced with death and serious illness, and the ending stories. My mother agreed to participate when she got sick.

It shows how far does a person's faith will carry them, do they keep their faith even after tragic, traumatic experiences? He's been a lifesaver for me. He got me right when I came back from the hospital, and I think there's some footage of me too when I was in the hospital.

During this time I met a lot of people who saw the documentary and a lot of people who went through the same thing I did, and they wanted to meet me and tell me they understood and thank me for volunteering for the documentary.

April was not only coping with the loss of her infant, but also the loss of her spouse. She had a cathartic experience after engaging in a ceremonial activity:

It didn't register, I didn't even allow it to be a second thought, it was like you know I almost took myself back from being in recovery after having one of the children; or I sprained my ankle or something or it was just something I was just dealing with. And I didn't...I couldn't do it...

Pain. Pain. When the reality hit me, again we had split up already for some time now, and I was in my home, I got a call from.... I got a call from a friend that his wife had passed. She too was a good friend. He wanted a woman to dress her, who knew her, and to prepare her for her casket. Okay great...I'd never done it before. I go to the funeral parlor and the family was already there, the husband was sitting outside with a little baby, a boy about a year old, and there she lay. She had passed giving birth to a baby. She had Sickle Cell and the report was that the doctor had advised her not to have anymore children. So, I along with another friend, we're caring for this woman and I remember being very sensitive and nurturing, and loving and carefully caring for this body; not till I got home and I was trying to go to sleep did it hit me, that was me, that woman could have been me, I was on that edge and didn't know it. And I spent the night just crying. I felt that had finally mourned the death of my baby.

Time as a Healer

Tina

Tina stated, "God has a way of working things out" in sharing her thoughts on what happened. This probably reflected, in part, a source of comfort during her grieving process. She stated:

It took awhile, I am fine now. Time heals; it's been almost three years. Things are much better between us.

Linda

Linda's process seemed to involve staying busy, and giving herself time to heal. She stated:

I just remember going back to work soon after and got distracted. There was a period when I wondered if I needed counseling, but just umm, decided to give myself time to heal, just kept moving. I am OK, and I think my husband is OK.

Moving On

Wileta's pregnancy was unplanned with a great deal of expressed anxiety surrounding the process of birth from the time of discovery.

Wileta's short response is interesting, and probably revealed a degree of relief:

When I lost the baby I was very upset about it, but I was like okay let's move on.

Freddie became pregnant only months after her loss, which may have inclined her to a more philosophical perspective, "Things happen for a reason." She really did not reveal much in relation to her grieving process:

We did receive a written apology with adjustment to our bill after writing a letter and making a stink over what happened. I am still very angry. Very sad, but I guess things happen for a reason. I don't know.

Delaying Action

Yvonne expressed needing counseling but has not moved on securing it. It is interesting that she used a similar strategy in dealing with stress, “I tried not to think about it during the first trimester.”

She stated:

And I know I needed to and I think I still do [seek counseling]. Mmm hmm (yes). But, and you know I think I do because...for various reasons. My husband is not the type of person to just open up and say okay let's talk, let's just let it all out. I have to be the initiator. And even when I'm the initiator it still isn't even to the extent that I need. Umm, of course he tries to make it all better, but it's just not same as what I'm looking for. Umm and I think the only way I'll get that is if I talk to another woman, who's experienced it or I don't know, I really don't know what's gonna help. Umm, but it still is a very. Pressing issue, emotionally, mentally and I think it also very emotional because we're still on the planning, or thinking about having another baby, and that fear of whether it's going to happen again. Could it happen again? If we were to have a child with a disability or problem, that's a fear. It's so funny, because when my coworker lost her baby I pulled up all these resources, and I said you have to go talk to somebody. And here I am going through it and I haven't.

And I have, and he's told me he says I know you need to talk about it and I need to talk about it. And I'm sorry I haven't because that's just the way I deal with things. Umm but I really don't think he is, not that he's not capable, but I don't know how.

Subsequent Births

It is interesting to note that there was at least one significant change in the lives of the 4 women (out of the 8) who had subsequent births, during the time period following their loss and prior to their successful pregnancy. Additionally, as mentioned, none of these women are representative of the 3 women who expressed feelings of disempowerment.

April

Although April was warned that it was unlikely she would have more children, she remarried and had two subsequent pregnancies:

Twice! And they said I wouldn't...shouldn't be able to get pregnant again after that. They were both full term, both natural births. One was 8 lbs. 6 oz. and the other was 7lbs. 2oz.

I can't say anything changed, except for a new husband. I am still working full-time, but at a different job.

Dorothy

Dorothy gave birth to a baby girl almost two years after the loss of her infant. Her husband was working in the US throughout her entire pregnancy. She stopped working after her first trimester and placed was on bed rest much earlier than in her prior pregnancy. She was diagnosed with gestational diabetes, and carried to full-term:

I'm thinking about it; in light of her being you know the only child. But I mean, with the pregnancy with her, I was out for like six months, so it was like you

know it wasn't bing-bam-boom: With her well, I had the stitch a lot earlier, so I had that and I got gestational diabetes. Yeah, you know it's like can't you just package it up and you know put it here.

Alana

Alana ended her long-term abusive relationship, remarried and moved to another state. Her baby was born full-term without complications:

Well I'm with someone new and we've been married for three wonderful years and he's the one you've been waiting for after all the hell, and he's great and we just have the one [child]. So there was three by my ex, and one with my husband. My baby was full-term without any problems, thank God.

Freddie

Freddie, who was approximately 15 lbs underweight, and worked nights at the time of her prior birth, gave birth this time without complications, to a baby girl. She explained the changes she immediately made when she learned that she was pregnant:

Yes. I did not really give myself a chance to lose the weight from the first pregnancy so I am much heavier although I don't feel that way. I feel good. I changed my work schedule. I am working days now. I eat breakfast every morning, and have a yearning for oranges. On occasion I have back pain, but not the kind of constant sickness I experienced during the first pregnancy.

Conclusion

This chapter concludes the four sections on findings.

The researcher explored the larger context surrounding the pregnancy from the time of preplanning to discovery and the role of medical and health issues on the pregnancy experience. Additionally, other areas included the women's perception of stress, its source and its impact on their pregnancy experience, and in this chapter, events, feelings and thoughts surrounding the event, pregnancy loss, healing strategies and subsequent pregnancies, for answers to the research question.

In this chapter, the women who suffered the loss of their infant took a reflective look back on what happened; sharing the event/crisis, their feelings surrounding the event, which might help in understanding their adverse pregnancy outcomes.

A number of interesting findings presented in this chapter are discussed more extensively here:

The first finding is related to the feeling of disempowerment, uncovered in the words of the women as they reflected on *why* the death occurred (i.e. "I really don't understand why it happened"; I "don't know what went wrong," "How can I stop this from happening again," "I really don't understand why it happened." Four of the women in this study shared such feelings.

It is also fascinating that of the 4 women who did not express feelings of disempowerment, all went on to have subsequent pregnancies.

Any feelings of disempowerment experienced by the women were not remedied by the doctors, who provided explanations devoid of information which could help the women understand why her infant did not survive (i.e. "It happens more than you think," "He gave me the statistics and told me not to worry," "Sometimes things just happen"). Five of the doctors provided explanations with little substance as to the reasons for infant loss. The exceptions were Dorothy's doctor who shared specific, albeit speculative, information, and Alana's doctor who provided a concrete answer, "Sometimes the muscles cannot support the weight". Linda's doctor provided no explanation.

In this study, of course all of the medical interventions tried, regardless of the level of expertise, timing and intensity, failed at stopping the premature births. Although, this target population suffered infant loss, the degree to which efforts were made to stop the pre-term birth must be mentioned, as it supports the growing medical concern that the current methods for the diagnosis and treatment of preterm labor are currently based on inadequate information about how preterm birth can be prevented (Behrman, 2007; Robinette, 1995). It also supports more recent research which questions access to care as an explanation for the rate of disparity between black and white infant deaths (Shi et al, 2004), and provides a clue on the disparity still persistent for women who have access to care.

There were also interesting findings related to subsequent births:

Of the 4 women whom had full-term subsequent births, all reported major changes in their lives (i.e. new husband, major move, and change in work shift, and weight). The women in the study also defied research findings which demonstrates that women who experienced an early preterm birth (<32 completed weeks) have the highest rate of recurrent preterm birth in subsequent pregnancies (Esplin, 2005). Four of the women who had subsequent pregnancies had full-term births without complications; although in Dorothy's case, much earlier medical interventions were applied successfully, in conjunction with noted changes in her life

Additionally in this study, there was a link between subsequent births and engagement in healing activities (i.e. counseling and ceremonies). Of the 4 women who had subsequent pregnancies 3 had engaged in these healing activities.

The majority of the women still did not make a connection between the stress they experienced, and their poor birth outcome. Only 2 referred to the stress they were experiencing, at the time of pregnancy, when sharing their thoughts on what happened.

The next chapter, VIII, will scrutinize the findings presented in the preceding chapters in the hope of discovering what it all means, and discussing the implications for Social Work practice.

CHAPTER VIII

Analyzing and Interpreting the Findings

This multicase study, using a sample group of eight black-American women, explored the possible reasons for infant loss in this target group. The primary research question, which guided this study is - *given the disparity in the infant mortality rates among middle class black and white women, are there factors attached to the pregnancy experience of middle class black women, which could help in understanding the adverse birth outcomes for this target group?*

This research is exploratory in nature and contributes new concepts and findings for further research on the BIM phenomenon. The more recent research suggests that the stress paradigm offers a perspective, which seems feasible in examining reasons for poor birth outcomes for this target group, in contrast to the poverty paradigm (Berg et al., 2001; Lobel, 2008; Mathews et al. 2002; Lu, 2008; Smedley, et.al. 2003). The researcher hypothesized that stress played a role in the poor birth outcomes for the women in this study, and the findings explicated in this study tend to support the hypothesis.

Each of the four preceding chapters on findings presented related research questions, which guided the exploration:

- *Are there variables attached to early pregnancy preplanning and discovery stages, which helped to shape the entire pregnancy experience, contributing to poor birth outcomes?*
- *Are there factors or issues imbedded in the black middle-class female experience, related to health issues and medical interventions, which could help in understanding the adverse birth outcomes for this target group?*
- *Are there unique experiences with stress, which might offer some understanding of the poor birth outcomes for this target group?*
- *Are there unique experiences, feelings, or thoughts, explicated by the participants' reflections on the occurrence of infant loss, which might add to understanding the adverse birth outcomes for the women in this study?*

The findings presented in the preceding chapters, largely satisfied these related research questions.

This chapter will analyze, interpret and scrutinize the findings presented in the preceding chapters in the hope of discovering what it all means, and the implications for Social Work practice.

The analytic categories below align with research questions and helps to organize the discussion:

- *The relationship between the meaning of pregnancy (preplanning and discovery stages) and poor birth outcomes*

- *Women's experience with factors associated with medical care and poor birth outcomes*
- *Women's experiences with stress and the sources of stress related to infant loss*
- *Women's reflections on the occurrence (loss) and the aftermath*

The relationship between the meaning of pregnancy (preplanning and discovery stages) and poor birth outcomes:

Personal Decision

The first area of exploration was in relation to the *meaning of pregnancy* for the women, which explored why the women wanted to have a baby, and to contextualize the individually-based factors that put these women at risk for adverse pregnancy starting from the preplanning and discovery stages (Link & Phelan, 1995).

One of the first themes that surfaced during this preplanning stage was the identification of a step, which occurred prior to the joint pregnancy planning between the woman and her spouse. The descriptions provided by the women revealed this first step to be a *personal decision* made by the woman to have baby or not have a baby, prior to talking it over with their spouse. What makes this important is that this personal decision seemed to create the conditions for negative tension at the starting point of pregnancy, if the decision was not in line with the practical realities of the woman's family. In all of the cases, where this

personal decision was evident, the women understood the contradictory reasons for not having a baby, which usually entailed practical and critical realities involving her family's circumstances (i.e. finances, other children, health, work schedules, etc.). Yet there seemed to be both external and internal factors, which served to influence the woman's decision regardless of the presence and weight of contradictory facts.

This finding falls outside of current research, except in relation to adoption. Curtis, 2004 suggests that the Social Worker plays a significant role in influencing the mother's decision to release her baby for adoption in contrast to the assertions by Social Workers that such decisions are based on mother's capacity to handle the loss. In as much as Curtis is referring to "outside influences," the finding here corroborates the notion of influencing or motivating factors in relation to the decision.

Yvonne was the first woman to pique researcher's curiosity about this as she spoke of an "unexplainable" desire to have a third child, which seemed devoid of a realistic assessment of her financial situation, the challenges of balancing work, children and a marriage, which she admitted were very difficult to handle. Yvonne talked about a longing to have three children, which should have been the case in her own childhood. She lost a twin brother at childbirth, "We were suppose to be a family of five, but were only a family of four." Her husband's stance, as conveyed by Yvonne, was clear. He was not able

to be the sole breadwinner, and still maintain their current life-style.⁶ In light of this, Yvonne continued to pursue this” unexplainable” goal- a third child- which did not seem to comport with a more reasoned assessment of family’s ability to incorporate an additional significant responsibility.

Another example was Dorothy, who repeatedly shared not being sure about the “wiseness,” of her decision, and expressed yielding to family pressure in making a personal decision to have a baby, knowing that her husband would be out of the county during her entire pregnancy.

As discussed in this chapter (IV), several women spoke of a range of influencing factors on their personal decision to have baby, or not have a baby. They presented their reasons and explanations to settle apparent feelings of discomfort or the dissonance created by their personal decision, and the contradictory facts surrounding their circumstances (Festinger, 1985). The following are two illustrations:

Yvonne:

We struggled with the decision to have the third, as I said before, umm trying to figure out whether it was the best for us, for our two kids that we have now...umm and this little baby that would be here, and we decided yes you all the deficits like the finances... time, was less than the joy of having the joy of having that third baby.

⁶ According to Census Report (2009), the number of stay-at-home moms declined from 5.3 million in 2008 to 5.1 million last year. That was the lowest since 2001, which was also during a recession.

Dorothy:

I was living at home, at that time we were living in a house, in a townhouse in [Newark]. So you know I didn't have any maintenance, they took care of the ground, they took care of the snow. So all I did was drive go, go out and come home. You know, most of my stressful interaction was just with umm, being at work, but I had that, wasn't necessarily unusual for me.

It is interesting that the women talked about *secrets* in relation to this personal decision. The researcher learned that the women (Yvonne, Dorothy, April and Freddie) never shared their feelings of ambivalence, fears and the pressures they experienced in relation to the decision to have a baby with their spouse during the joint pregnancy planning phase, nor later. This underscores the fact that such personal decisions were a separate step in the planning process, and private.

Unplanned and unwanted pregnancies

There is significant research, which demonstrates a link between mothers' attitude toward having a baby (intended vs. unintended pregnancy) to pregnancy outcomes, regardless of socio-economic status (Kost, 1998; Pagninni & Reichman, 2000). Women who want their babies have coexisting behaviors and attitudes consistent with promoting a positive birth outcome. (Kost, et al.,1998). Three of the women in this study had unplanned pregnancies and 2 were unwanted (Alana, Tina).

All of the women with unplanned pregnancies experienced psychosocial issues throughout their pregnancies. One woman, Alana,

was involved in a long-term abusive relationship (Root, 1996; Niggers, 2004; Tiwari, 2008)). Tina provided descriptions, which revealed symptoms attached to depression (DSM IV, 2000; Thomas, 2009) and Wileta spoke of serious anxiety in anticipation of the delivery of her infant (Wadhwa, et al., 1996). None of these women (3) was engaged in professional counseling (Warren, 1997).

All 3 women represented the 5 women who spoke about having problematic relationships with their spouse.

Emotional Support

Family

All of the women, with exception of Wileta, described positive ties with their families and felt supported by their families throughout their pregnancy. All of the women, who explicitly referenced family and culture in shaping self-expectation, had successful subsequent births. This is consistent with research findings, which identifies family support and a connection to culture/social support as protective factors (Jackson, 2005; Lobel, 2008). It is interesting that the strength of such protective factors did not change the pregnancy outcomes for the women in this study.

Spouse

There is growing research, which demonstrates paternal involvement as a protective factor against low birth weight and infant mortality from the preconception phase (Gaudino, 1999; Pagninni & Reichman, 2000; Frey, 2008). Given this fact, more attention on exposing and educating black men on issues involving BIM is an increasing interest (Quinn, 2008).

Three of the women this study did not feel supported by their spouse during the discovery stage of their pregnancy. Two of these women had unplanned pregnancies, and it is also interesting that these same women represented the 4 women who did not have subsequent pregnancies.

The women shared various reasons for not feeling supported by their spouse, which reflected problems in the marriage, probably exasperated by news of a pregnancy (Hogan & Ferré, 2001). All of the women were part of the 5 women who talked about having problematic relationships with their spouse.

Key Events

This area allowed for an exploration on what was happening in the woman's life during this early stage of her pregnancy. What were the occurrences, who were the people, what were the circumstances, what

were the some of the probable factors that put her at risk for a poor birth-outcome?

The women recalled events that were of particular importance to them during this period. Although, not all events were negative, most were. An absent husband, death of a loved one, a seriously ill mother, and the move of one's parent out-of-state, an important job promotion poorly timed, were the kind of events that loomed large in the background for all 6 women throughout their pregnancy. These are the kind of events, which when combined with other "life stressors" causes negative physiological stress reactions (Lobel, 2008; Troxel, 2003; Lu, 2003).

In summary, this chapter revealed an *imbalance* in the lives of the women during this preplanning and discovery stages of pregnancy. Things were out-of- kilter: a decision to have a child in light of contradictory facts, an abusive relationship, an absent husband, an unsupportive spouse, feelings of depression, etc. For each woman there were at least two significant factors present, during these early stages of pregnancy, which contributed to imbalance in their lives, creating the conditions for increased susceptibility to prenatal maternal stress (Giscombe, 2005; Lu, 2008).

Factors associated with medical care and poor birth outcomes:

Doctor selection, relationship with doctor, and race:

The issue of race is prominent in the research as an important factor in explaining the disparity between black and white health outcomes in general, and black and white differences in the infant mortality rates specifically (Giscombe, 2005; Harrel, 2000; Mustillo, 2004; Williams, 2000, Smedley, 2003). According to a vast amount of research, race plays a significant role in the quality of care issues (i.e. time spent with patient, the quality of patient/physician relationship, the degree to which specialized services are rendered, etc.) affecting health outcomes across the medical spectrum (Cromwell, et al. 2005; Cooper, 2003; Todd, et al., 1994)). In this study race did not initially appear to play a role in the delivery of care, but was implicated in the quality of the communication between patient and doctor. However, as the researcher analyzed the findings, the role of race became increasingly suspicious, especially in the area of quality medical of care.

First, race and gender was at the center of the thinking of the women when it came to selecting their doctors. The majority of women apparently made a connection between concordant race and gender between patient and physician to quality of care, and took action to ensure that their primary medical care providers were black and female (Cooper 2003). This target group had the flexibility and power to exercise this choice, although it is not clear if the choice had any

influence on the final birth outcome. The women seemed to be looking for an emotional connection with their doctors, starting from a race and gender commonality, where the communication felt comfortable. However, this level of comfort may have skewed their perceptions of the actual quality of services they were receiving, and allowed them to accept doctor's responses, which were often in contradiction to how they were feeling, and what they were sensing (Bennett, 2006). What is clear is that the women felt, for the most part, satisfied with the quality of care, and had a good relationship with their doctors.

This "good feeling" relationship with their doctors was evident, even if the doctors they selected, because of race and gender, did not end up as their primary physician. In these instances, there were no expressed complaints and the favorable feelings toward the selected doctor transferred to the assigned physician. From the women's perspective, what they set out to accomplish in their doctor selection, a positive relationship, they achieved.

Warning Signs

The majority of the women in this study had medical complaints lasting throughout their pregnancies. In examining the consistency of complaints made by the women, on medical symptoms (with very similar language used across the board), and the responses of their doctors (with very similar language used across the board), and the kinds of medical

interventions applied, there seemed to be a repetitious interplay between women's complaints and medical responses with no good results. It is interesting that, for the most part, the women maintained a trust in their doctor's judgment, even leading to temporary periods of reduced anxiety in relation to the medical symptoms they were experiencing, because the doctor assured them that, "everything is fine," "all is OK."

Warning Signs: Growing Concerns

Dorothy makes an interesting statement, in her role as physician, related to this point as she reflected on the medical care during her hospitalization, and on factors she feels are embedded in patient/doctor relationship, which is apropos to this discussion:

I think that to a certain degree for various reasons people put a lot of credence into the doctor. Well the doctor said everything's fine so it must be fine, well the doctor said so, so it is...and in that happening that also gives them [MDs] the ego to feel like, I said there's nothing wrong with you, so there's nothing wrong with you. Umm.

This observation reflects an almost tacit agreement between patient and doctor on the traditional rules, which frame this professional relationship; I talk, you listen. The doctors may possess an attitude of authority, part of their professional culture, making it difficult to question the information provided (Cooper, 2003; Smedley, et al., 2003; Travaline, 2005). Culture is a concept not limited to patients, but also applies to the professionals who treat them. Every group of professionals embodies a

“culture” in the sense that they too have a shared set of beliefs, norms, and values.

There are still additional issues, which are sources of concern more attached to the quality of doctor’s information on what effective medical actions to take in response to the common complaints, like those posed by the women in this study.

There is growing concern that the basis for diagnosis and treatment of preterm labor relies on inadequate information about how to prevent preterm births (Behrman, 2007; Herbert & Robinette, 1995). The most common treatments, as used on Dorothy and Alana, usually applied during the final weeks of pregnancy, focuses on slowing down contractions. This approach, according to research, has not reduced the incidence of preterm births but has delayed delivery long enough to allow for the administration of drugs for lung maturation and the prevention of respiratory distress, which are reported to be effective in selective cases; but not for any of the women in this study (Behrman, 2007; Ross, 2009).

Two of the women, Dorothy and Alana, received progressively aggressive medical interventions starting from around 24-25 weeks of pregnancy, aimed at stopping pre-term births. Dorothy was the only woman given a diagnosis, related to a short-cervix, near the end of her pregnancy, which she explained, was by then too late to reverse her premature birth (Goldenberg, 1996, Ross, 2009). Her subsequent

successful pregnancy underwent the same interventions applied much earlier, which included a leave from work after her first trimester.

Dorothy's diagnosis, short cervix, is an optimal predictor of preterm delivery in low-risk women, according to growing research (Ross, 2009). Some researchers have recommended that doctors consider performing baseline ultrasonography to assess cervical length, especially at 13-17 weeks' gestation (Caglar, 2005; Ross, 2009; Iams, et al., 2009). Since Dorothy had no prior births, there was no history regarding the evidence of this problem. However, to assess for cervical lengths of those women identified at-risk for poor pregnancy outcomes, and who present medical complaints, could help to expand the period of gestation, thereby decreasing the rate of pre-term births (Behrman, et al., 2007; Ross, 2009).

Dorothy's high-risk doctor shared information colleague- to - colleague after her loss, which corroborates the view of inadequate information on prevention the prevention of preterm births:

You know there is some information about heredity and incompetent cervix and about six percent of people, it's not a well defined type of thing just tissue protoplasm strength blah, blah, blah, so he said they may have been a contributing factor. Which of course in the traditional way of training actually people don't really talk about that as being a significant factor for other women delivering pre-term. Therefore, it is not something that you really focus on, or is documented very well in literature.

Warning Signs: Broader Context

It is important to place this part of the discussion in a broader context. The National Academy of Sciences (2006) called for more targeted research and treatment alternatives in the field of Obstetrics, while also pointing out major obstacles to conducting clinical research. Such obstacles include the declining number of residents interested in entering the fields of Obstetrics and Gynecology, having an affect on the pipeline of clinical researchers. The rising medical malpractice premiums and the ability of academic programs to provide 'protected time' for physicians to pursue research have consequences on quality of care issues. Such facts expose a medical specialty facing unique challenges.

Warning Signs and Physician Attitudes

There are other issues. Studies demonstrate that the doctors' lack of effective intervention may reflect the lack of preparedness to hold substantive conversations with women around behavior or other health-related changes to ensure a positive birth outcome (Marshall & Jan, 1990; Smedley, 2003). Throughout this project, the researcher took note of the simplistic quality of doctors' responses and explanations, which did not seem to appreciate their patient's education level. This may reflect an effort to keep it simple to avoid causing concern. On the other hand, it may reflect a physician culture entrenched in attitudes attached

to authority and superiority and personal biases (Lewis, et al, 1990; Todd, 1994; van Ryn, 2000). There are efforts in the field of medicine to close the gap between actions linked to “ professional culture “which often do not match the needs of the patients; the consequences are just too high (Johnson, 2004; Kundhal, 2003).

Additionally, black women have so many pregnancy and infant losses, and it is likely that his fact, in a broader context, plays a role in shaping physician’s attitude in relation to BIM. According to the women’s accounts, there were no in-depth conversations about the severity of their medical complaints and only one specialized test ordered. There may be an acceptance to expect a certain amount of failed pregnancies, based on race (Delgado, 1991). This in turn affects the manner in which the doctor responds to medical complaints and presents information. This is unbeknownst to the women, and this form of disparate care, may be automatic without conscious awareness by the physician, and carried out by white and black physicians, as issues related to BIM become accepted consequences in the Obstetrics practice (Chin, et al.,2001 ; Cooper, P. 1999; Williams, 2000;).

The simplistic explanations provided by the doctors in response to warning signs may also reflect a lack of current knowledge around new and more effective interventions in addressing infant mortality, as mentioned above.

Warning Signs: Body's Alarm System

There is still something else troubling about *warning signs*. Warning signs were the first indicators that something was not right; the women believed that, the body's alarm system was working fine. This means that the women had to attempt to turn off their body's warning system to accept the medical advice. April stated a consequence, "So I don't totally understand my body anymore after that."

The implications on the effect these kinds of experiences with the medical profession have on a black woman's psyche are troubling. What surfaced from this study was a trust in the doctor, contrary to body's warning signals. How the dissonance between what is internally experienced and what is medically shared gets resolved is hard to decipher. In April's case, as revealed by her words, there is now distrust in her body's internal warning mechanism. Dorothy's previous statement suggests that doctors' words are given a great deal of credence, which may not be deserved. Just as the basis of the positive and trusting patient /physician relationship, did not appear to match the quality of care.

Precipitating Causes:

The degree to which the women in this study experienced *precipitating causes* was an unexpected finding. There is no etiology

attached to these causes, they are simply participatory occurrences resulting in unforeseen consequences; the question is why?

This is one of the few areas -*precipitating cause* - associated with poor-birth outcomes within the women's realm of control. This is especially true if they are aware of the kind of activities that could put them at risk (Mirsa, 1998; Juhl, 2007). Alana, for example, actually experienced the precipitating cause while being on restricted activity as per her doctor's instruction. The realities of life, climbing up eight flights of stairs to her apartment due to a broken elevator, clashed with the medical restrictions, which resulted in an emergency hospitalization by the end of the evening. This may reveal a larger issue as noted in Alana's account. Her doctor only explained that she was 'carrying low' because her muscles were relaxed due to prior pregnancies, "She just told me to take it easy." The doctor may have been more concerned about the health of the fetus, than she revealed to Alana, but the point is that Alana did not seem to appreciate the possible consequences of climbing up eight flights of stairs (precipitating cause). This calls attention to the quality and kind of medical information imparted to the patient by the doctor (mentioned above) which could help in preventing precipitating causes.

Additionally, with knowledge of a short cervix and the possible risks, the probable contraindicated trip and the excessive physical activity Dorothy engaged in while in New Orleans was avoidable (Misra, 1998).

Possessing clear information, as the result of more in-depth inquiries and tests, probably resulting in a diagnosis could avoid or reduce involvement in precipitation events.

Blame

Blame usually connected to the grieving process, was not the case in this study, as there was considerable time between the loss and participation in the study, for the majority of women. Here feelings of blame were linked to *precipitating causes*. The reason for this may reflect the women's freedom to decide whether to participate in the precipitating event, and they tended to blame themselves for that decision, "I over did it," "I should have talked to her (doctor) earlier." The blame had a self-attribution of responsibility quality specific to this single factor, precipitating cause.

Yvonne was the only woman interviewed within six months of her loss, and appeared to be struggling with issues around her loss. She was still in the process of working through feelings of blame, which she attached to her husband, first for allowing an argument (precipitating event) to reach a level that was "stressing me out," and alluding to a link between her husband's medications to treat high blood pressure to their infant loss. Although Yvonne recognized the need for counseling, she had not entered into counseling at the time of interview, or at the time of

subsequent contacts. She has put off plans for a subsequent pregnancy recognizing the existence of unresolved issues.

Paternal Family History

The prominent role of the paternal family history implicated in preterm births and infant mortality in the pregnancy stories was an unexpected finding. What is interesting is the evidence of paternal involvement as a protective factor (Gaudino et al., 1999; Frey, 2008; Quinn, 2008; Barnes, 2008) against adverse birth outcomes, while conversely, in this study, implicated in adverse birth outcomes. The majority of the fathers had a family history involving both preterm births and infant loss. There is very little research on paternal family history implicated in poor birth outcomes. In fact, the little research, which examines paternal factors in relation to adverse birth outcomes, reveals negative associations between paternal factors and adverse birth outcomes (Varner, 2005). One exception is research on paternal age as a factor linked to LBW infants. Reichman's (2006) research findings demonstrated that fathers older than 34 years were 90% more likely than fathers aged 20 to 34 years to have LBW babies. Five of the men in the current study were 34 or older; therefore, age is a possible contributing factor. Nevertheless, the fact that out of the 7 men whose family history was known (1 father was adopted), 6 had preterm and infant deaths in their family history is significant.

There is much ground to cover in bringing black men into the fold, on the issue of BIM. History and culture serves as obstacles, as issues related to pregnancy traditionally remain in a domain assigned to women, and supported by women, as revealed by some of the statements made by the women in this study, “You don’t think that men, connect with the babies as you’re carrying them. He was definitely connected with this pregnancy and that baby,” “You know the fact that he wasn’t there at that time, in my mind wasn’t an issue, because I could go home, I could go to sleep and not have to do anything.”

Additionally, BIM is an issue not known to the black male community, (Quinn, et al., 2008). The interesting way that the women learned of their spouses’ family history in connection to their infant loss was as if the men and family members were sharing secrets. This was an interesting dynamic and it is unclear what this reveals besides feelings of uncertainty if such information would even be relevant and appreciated.

It is clear that direct input from fathers is missing from this research and from much of the research. The importance of the fathers’ perspective is important, as is their role as a protective factor against adverse birth outcomes.

Summary

The layers of meanings that emerged from the numerous findings in this chapter (V) are complicated. An important insight uncovered, relates to the “routine” treatment and deficient communication provided to the women by their doctors, which supports the view of inadequate information on diagnosis and treatment to prevent preterm labor for the women in this study (Behrman, 2007). The warning signs were precursors to trouble and probably a signal for more than routine tests. There seemed to be missed opportunities for more in-depth inquiries and specialty testing, likely resulting in a diagnosis. Wileta was the only woman referred for an amniocentesis. The other specialty high-risk services, rendered to Alana and Dorothy only weeks before their loss, if provided sooner could have resulted in specific restrictions avoiding precipitating causes.

Additionally, researcher suspects that race played a role as the frequency of pregnancy losses by black women likely influenced the attitudes and the quality of services and communication of the doctors, as discussed (Lewis, et al., 1990; Smedley, 2003; Johnson, et al., 2004). Moreover, placing BIM in the context of a medical specialty facing problems related to research, training and attracting new physicians, is an unfortunate set of circumstances layering a complicated issue. However, the women, for the most part, remained pleased with their doctors, unaware and unaffected by these issues.

Women's experiences with stress and the sources of stress related to infant loss

Prior to a specific focus on exploring the women's experiences with stress, the beginning pathways of stress and the probable outcomes of stress emerged, as discussed in the preceding sections. Although the experience of stress was an area of planned exploration, the degree to which themes attached to stress emerged prior to this chapter (VI) was unexpected. The discussion in this section clearly builds on an emerging theme related to stress, and begins by asking - why were women in this study so susceptible maternal stress?

Much of the research and literature on the experience of stress for black women demonstrate chronic exposure to life stressors, just by virtue of being black, regardless of socioeconomic status as depicted in the below account shared by Dorothy (Thompson, 1996,; Root, 1996; Lu, 2003; Troxel, et al., 2003; Giscombe, 2005).

Dorothy

.....because that's just...you're used to being.. you haven't gotten here by not thinking that people are racist, or not thinking that people are prejudiced against you, not knowing that people have pre-judged you. That's what you deal with, that's what you have dealt with every day of your life.

Dorothy's description aligns with the "weathering" construct, which provides a feasible explanation for disease and adverse birth outcomes due to internalization and chronic exposure to stress. In dealing with

racism “everyday of your lie,” a chronic stressor, the body prematurely ages making women susceptible to poor birth outcomes (Geronimus, 2001).

The unique experiences with stress surfaced during a focus group meeting for an unpublished pilot study by this researcher (same topic and target sample) conducted in 2001. One of the members provided a mesmerizing description depicting her struggle at balancing a high powered job, marriage, two children, being the primary breadwinner, at the time, and pregnant. Threads of her story repeated in the pregnancy stories of the women in this study, with the most compelling theme related to the notion of self-expectation, infused with a racial history, which is a theme that surfaced at the beginning of this area of exploration.

There were questions on how to situate this idea- *self-expectation*- as it seemed rooted in a racial history (Herndl, 1995). Is it a coping behavior or an issue worthy of a much larger context, as it seemed to shape the women’s perspective on the experience of stress in their lives? The tension between self-expectation and stress soon surfaced, as the women’s words revealed the starting place, or the source of their developed sense of self-expectation. It appeared difficult for the women in this study to give full value to the effect of stress in their lives with an “ingrained” sense of almost supernatural powers to do it all, like their mothers, and the women before them. It does not matter that, in most

instances, they did not mention a more distant history shaped by racism. We are hearing from women several generations away from “the scene of the crime,” but still influenced by, and still using coping behaviors passed down through generations, designed to counteract racial stereotypes, especially related to pregnant black women (Root, 1993; Solinger, 1990, Degruy, 2005). The words of the women provided the context and the connections to history, and a unique perspective on their coping behaviors and experience with stress.

The women in this study gave verbal recognition to the presence of stressful events and situations in their lives but, for the most part, did not link stress to consequences involving their health or the health of their unborn baby. Five of the women spoke of self-expectation in relation to history, culture and family. How does one give value to and/or fully recognize the stress in one’s life, while needing to perform in a *business as usual* manner, reflecting an expectation of self? This researcher asserts that part of the tension was resolved by employing, what seemed to be, ineffective coping behaviors in relation to stress, which did nothing to reduce stress, but made the women feel more in control over stressful events in their lives.

Sources of stress surfaced as the women revealed a range of observed emotions when talking about the lack of financial options connected to wanting time off flexibility and problematic issues with spouse. Other sources of stress were evidenced as they possessed inherent qualities,

which produced measurable stress responses, as in the case of medical symptoms (warning signs), and secrets (Sable, 2000; Wadhwa, 1996; Wegner, 1987).

Stress related to race emerged in interesting ways. The women tended to allude to its presence rather than refer to specific encounters with racism, or their specific feelings about racism. The “If I were white,” statement made by Carla is loaded with meaning, and encompassed layers of thoughts connected to a racial history. The researcher is a black- American, and perhaps the women felt the issue could stand with limited explanations.

It was interesting that when Dorothy, for example talked about her experiences with racism, it was so imbedded in a long account that the meaning of her words were not fully understood until transcribed. In talking about her treatment at the hospital, it was difficult for her to admit that race probably played a role (Harrell, 2000). Crosby (1984), talks about the need for blacks to believe in a just world, and the fairness of others, to avoid feeling vulnerable and powerlessness. Going back to Carla’s description, perhaps the reason she did not ask for car service was due to her race, and she did not want to risk testing the fairness of others. It would be particularly important for the women in this target group to maintain a sense of power, and not seen as vulnerable. The responses to racial issues could reflect a stance more prevalent among blacks comprising middle-and upper middle class

groups. Their “status” makes contacts with white authority prevalent with more at risk. Viewed as powerless or vulnerable could have serious consequences. However, the well-documented link between racism and poor pregnancy outcomes exists regardless of how the women chose to reveal their feelings or encounters with racism, and does not obviate its influence and affects on one’s health. Such feelings still reside in the psyche with physiological consequences (Hogan & Ferré, 2001; LaVeist, et al. 2000, Lu, 2003).

Warning signs: Source of stress

Warning signs, discussed here, as a source of stress and in the preceding Chapter (V) were outcomes of stress. This speaks to the insidious nature and the cumulative effect of stress. For example, Yvonne believed that by delaying anticipatory thoughts, related to planning for her baby, she could cope better with stress. She instead was producing more stress by experiencing and anticipating it (Wegner, 1989; Jackson, 2007). Linda who talked about “only letting in a little [stress] at a time,” was involved in trying to suppress unwanted thoughts she felt would be stressful, but instead was involved in a thought cycle where the suppression actually increased the frequency of the thoughts (Wegner, 1989). So on top of the more obvious sources of stress, the women were engaged in processes that were actually increasing the frequency of stress responses.

Warning signs were particularly troubling issues for the majority of women who suffered such symptoms throughout their pregnancies, and was at the center of much of the communication between the women and their doctors. For the majority of the women warning signs were severe and persistent; several women experienced and shared feeling that was something was wrong, and others shared feelings of anxiety, worry, and fear, all triggers for measurable stress responses causing negative physiological changes, usually not known to the women (Lobel, 2008; Wadhwa, P.D. et al., 1996; Yali 1999).

Secrets

Secrets surfaced as a theme at different times during this research project, and were clearly a factor in the lives of the women in this study. Secrets in relation to the pregnancy contained similar feelings as those attached to warning signs (fear, anxiety, and worry). Alana talked about her and her mother being the keepers of her secret about her abusive husband. Freddie's secret was in relation to an abortion in the past, which was haunting her throughout her pregnancy. The feelings attached to secrets produce a similar stress response as those feelings attached to warning signs (Pennebaker, 2003). Both secrets and warning signs were stress factors simultaneously present throughout the pregnancy for the majority of the women.

The Job and Stress

It was surprising to learn that the majority of the women in this study did not identify their job as a source of stress, but rather a place of support where close friendships existed. This might be a somewhat different experience for this target group, compared to Black women of lower socio-economic status. The women in this study were educated professionals in jobs of choice (except for Tina and Alana).

The women also did not cite job security as a source of stress, which was somewhat unexpected given the current challenging economic conditions. According to the Bureau of Labor Statistics (December, 2010), the current unemployment rate for black women is 13.1% compared to a rate of 7.4% for white women over age 20, and 14.7% for all blacks, compared to 8.7% for all whites, same age. Based on the realities of the current state of the economy in the US, the women in this study may possess a false sense of job security, or because of the nature of their work feel so valuable to their organization not be concerned about job security. Nonetheless, it is interesting that neither the job, nor job security were identified as sources of stress for the majority women in this study.

Financial Options

What did emerge as a source of visible feelings of frustration, disappointment, and in some cases, anger was the lack of financial

options that would permit extended time off during and following pregnancy. The frustrations expressed by the women in this study seem rooted in facts, as illustrated by the longstanding racial ‘wealth gap’ which makes African- Americans particularly vulnerable when job loss strikes, or in this case, when seeking financial options for extended time off. The Survey of Consumer Finances collects data every three years on the wealth gap and every time it demonstrated the racial wealth gap has widened. In 2004, for every dollar of wealth held by the typical white family, the African-American family had only 12 cents. In 2007, it had exactly a dime for every dollar (Ehrenreich & Muhammad, 2009).

African Americans, poor and non-poor alike, possess relatively few financial assets. Most have little financial cushion to absorb the impact of the social, legal, or health-related adversity, or elective time off from work (Surgeon General Report, 2001), which makes this a differentiating factor for blacks in relation to infant mortality disparity.

Although all of these women held full-time professional employment, it was clear that, for the majority, both salaries were necessary to maintain their life-style, and access to “money put aside” was not available to the majority of the women. For the most part, the women, although frustrated accepted their reality. Yvonne, who had the “unexplainable desire” to have a third child, was the only woman who shared posing the issue of extended leave to her husband, with disappointing results, “. I’m sorry honey but we’re not at the point where

I can be the sole breadwinner, umm and still live here in New Jersey and still have the things we want to have.”

Relationship problems with spouse

A pregnancy exasperates stress responses within many aspects of life, including but not limited to family, partner relationships, children, community, work, housing, and income (Hogan & Ferré, 2001). The majority of women in this study shared a range of difficulties with their spouse from communication issues, to infidelity and abuse. Some of the issues were evident early in the discovery stage of pregnancy. All of the women (3) who revealed not feeling supported by their spouse early in their pregnancy, represented 5 who shared having problematic relationship issues with their spouse. Wileta and Yvonne shared feelings of frustration due to their husbands' inability to talk more openly about issues important to them. Linda and Tina talked about issues centered on infidelity. Although April did not express any problems between her and her spouse, his behavior and departure shortly following the loss, suggested that there were issues in the marriage. In Alana's case there was an almost ten-year span of emotional and physical abuse.

In summary, the overriding finding in this chapter is the exposure to significant life stressors in important areas of the lives of each of the women (finances, marriage, health, home), and a unique perspective on how they experienced and dealt with such stress, which seemed linked to

family, culture, history, race and a sense of self-expectation. This perspective could have affected their ability to connect their experiences with stress to health consequences for themselves and their unborn fetus. Additionally, the fact that the majority (6) of the women in this study had prior successful pregnancies, may have affected their perception of the role of stress in relation to their pregnancy loss. This is an area, which falls outside of the current research.

The findings reveal a cumulative combination of negative factors attached to stress responses present throughout each pregnancy experience, having a negative impact on birth outcome (McEwen & Stellar, 1993; Lu, 2003).

Women's reflections on the occurrence (loss) and the aftermath

The women offered the information in this section with little to no prompting from the researcher, but as natural endings to their pregnancy stories, which started with events immediately prior to infant loss. All of the occurrences took place in a hospital, and with the exception of Dorothy and Alana (already hospitalized), all were the result of entering the hospital on an emergency basis. For 5 of the women their personal doctors attended to them, but arrived after examinations and interventions took place. Wileta's doctor was not present during her emergency. Four of the women were alone at the time of the event.

It was interesting that the time of the occurrence did not seem to matter, the emotions attached, although monitored, were evident, and the details recalled were impressive (Peppers & Knapp, 1980). There may have been areas where the time sequence was off, but the information seemed accurate, and was consistent with other descriptions with overlapping information.

In some cases, women gave descriptions, which included preparations in relation to the burial of infants, in most cases they did not. Researcher was careful to go only where the women's reflection wanted to cover, due to the emotional sensitivity of the information.

The women recalled being in a state of high anxiety, fear, in relation to this unexpected trauma. As Tina stated, "It hit me like a Mack Truck!" There was very little time to process all of the events and factors occurring rapidly during this period, which for some of the women, was exasperated by the absence of their spouse or close family member during the initial, but critical period.

A feeling of what this researcher labeled 'disempowerment' was the first theme to surface. In other words, the experience of having power taken away, as revealed in the words of the women following their recollection of the loss of their infant (i.e. "I really don't understand why it happened," "I don't know what went wrong," "How can I stop this from happening again," "Why did this happen to me?"). Such feelings of disempowerment may have lasting consequences (much like the feeling

of not being able to trust, one's internal warning system). Therefore, the next theme to emerge, in relation to doctors' poor explanations to the women on why they lost their babies, was especially disconcerting. There seemed to be a missed opportunity to reduce feelings of disempowerment, that upon further review was directly tied to the woman's ability to move on in certain areas of her life (none of the women who expressed feelings of disempowerment had subsequent pregnancies) for the women in this study.

The women talked to their personal doctors about their loss, usually at the hospital. Wileta's doctor contacted her via telephone. The doctors' explanations on why the women lost their babies lacked substance (i.e. "It happens more than you think," "Sometimes things just happen"). Here again the doctors seemed not to take into account the women's level of education. An alternative explanation is that the doctors also lacked information on what happened, or the way in which these incidences are treated are routine including the explanations. There are numerous possible explanations, but the result again was a gap between information needed and the information received (Smedley et al., 2003; Johnson, et al., 2004; Bennett, 2006).

Some of the women in this study referred to God and spirituality in reflecting on the reasons for their loss. Although, the other women did not openly express such feelings, there were indications of their faith (picture of Jesus on the wall, a cross-worn, etc.). Therefore, the women

in this study support other research findings, which call for professionals to be cognizant of the important role of spiritual and religious beliefs in providing services to women following infant loss (Van, 2001).

The findings in this chapter also revealed interesting links between subsequent births to active involvement in healing strategies, and the ability to make significant changes (Van, 2001). Half of the women in this study had subsequent full-term pregnancies, inconsistent with research findings (DiNitto, 1991; Esplin, 2005; Rowley, 1994). All of the women (3) who were actively involved in healing strategies (professional counseling, burial ceremonies) represented the 4 women who had subsequent successful pregnancies. Freddie should probably be included with the number of women actively involved in healing strategies. She made a decision to become pregnant soon after her loss, which was her approach to healing. The women who reported no significant change occurring in their lives were not part of the 4 who had subsequent pregnancies.

For the most part, the endings to the pregnancy stories did not include recognition that stress could have played a role in the poor birth-outcomes. This underscores the fact that although the evidence of stress was prevalent throughout the pregnancies, and the women recognized the existence of stress occurring in their lives, the value placed on stress and its consequences is minimal. This has important implications on interventions for expectant mothers. The women talked about

precipitating events, speculated on possible medical causes, with two mentioning stress as a possible factor. Others remained unsure and baffled as to the reasons for their loss.

In summary, the important overriding findings in this section (chapter VII), which underscores the findings in preceding sections, is the important but lacking role played by the doctor, not only as medical technician, but also as the informed expert, able to impart useful, important information in a sensitive and timely manner. Additionally, this chapter supports the findings, which suggests that the women tend to devalue of the effects of stress on in their health in general and specifically in relation to infant loss.

There are themes attached to resiliency, as the majority of the women of this target group made significant life changes, had subsequent pregnancies, and some had improved relationships with their spouse as cited by Tina: “It took awhile, I am fine now. Things are much better between us.”

Summary of Interpretation of Findings

As the pregnancy stories unfolded, in every case the weight of each negative factor continued stacking up, one by one, leading the researcher to the question at what point does it all reach a point where it is just too much to bear - resulting in infant loss (McEwen & Stellar, 1993; Seeman et al., 2002; Lu, 2003). The discussion reveals the preponderance of negative factors, experienced by all of the women in varying degrees, and much of which appeared linked to stress responses, which offered an understanding on possible reasons why the women in this study lost their infants.

A medical diagnosis assigned in one case, albeit late, caused suspicion about undiagnosed medical factors implicated in other cases. However, even without known medical variables, as the pregnancy stories progressed, with the combination of negative factors, each pregnancy took on an almost predictive nature. Although there were mediating variables (i.e. emotional support from family, a positive connection to work, trust in doctor, educated, married and employed, etc.) the strength of the negative variables, which were cumulative, proved difficult to overcome (McEwen & Stellar, 1993).

There was an initial impression of *imbalance* in the lives of the women during preplanning and discovery stages of pregnancy. Things

were out-of- kilter and opened an easy pathway for other negative contributors to enter.

The concern expressed that the basis for diagnosis and treatment of preterm labor relies on inadequate information on how to prevent preterm birth and/or or the lack of early more aggressive medical intervention based on current information, are probably evidenced in the medical treatment received by the women in this study. Such care relied on “routine” tests and provided communication with little substantive information (National Academy of Sciences, 2007). This fact in combination with other dominant findings (i.e. paternal history; key events, lack of spousal support, precipitating causes), including exposure to life’s stressors presented cumulative risks from various sources affecting pregnancy outcome for the women in this study (McEwen & Stellar, 1993).

The reflections on events surrounding the loss, again highlights the need for the doctor to be medical technician and informed expert to provide effective care and to help the women better understand the possible reasons their loss.

The healing strategies discussed, corroborate other research studies, but also reveal a possible connection between active involvement in healing activities (i.e. bereavement ceremonies and professional counseling) to subsequent successful pregnancies; an area worthy of further research.

The findings in this study relates only to its sample and raises questions, points to areas for more research, provides some new insights, and a deeper understanding on the context of the women's life from the beginning stages to the end of her pregnancy.

This is a reflective study on past events, increasing the chances of inaccuracies. However, research demonstrates that the women usually recall the events surrounding the loss of an infant in detail (Hogman, 1985).

The researcher was also acutely aware of her personal familiarity with the subject, and identification with the target group, which allowed for a deeper insight behind the meaning of the data, but also increased the potential for biases in analyzing the data. To help minimize this limitation, throughout this study the researcher engaged in ongoing critical reflection through journaling and discussion with colleagues and dissertation advisor. However, researcher recognizes that others might reach different conclusions, and tell a different story.

It is also important to note the difficulty experienced by the researcher in the recruitment of participants for this study. In contrast to the efforts made on various fronts, including the use of several professional listserv groups, social networking, church, agency and physician office contacts, etc. the results were small by comparison. The sensitive issue under study, combined with a targeted population usually seen privately for OB/GYN care, which was initially viewed as the best

source for referrals, was not readily available for the kind of personal inquiry necessary for this research. This presented unique challenges in the recruitment process for this project. The fact that it took almost nine months to secure 12 subjects, with 8 appropriate for this study finally identified, is a fact worthy of attention as it may have implications for treatment and educational outreach for this target group.

A primary issue was that researcher had to rely on others to deliver the “message” in relation to the study, rather than having direct access to possible participants. Eventually, all of the efforts yielded results, most often, indirectly through people first learning about the study via the efforts above, and then identifying someone, they had personal knowledge of having experienced the loss of an infant. The least helpful recruitment source was OB/GYN physician practices.

Implications for Social Work Practice

The Social Work profession brings a history and a special interest to bear on this topic, as it was at the forefront in educating women on issues related to infant mortality, and the first to identify the black and white disparity in the infant mortality rates (Combs-Orme, 1998). Although, there is an enormous amount of research required by the field of Obstetrics to address the prevention of preterm births (predominate cause of infant mortality for blacks), the issues impinging on the women

in this study were largely psychosocial. This study identified the following areas and issues for additional qualitative research:

Exploration of factors influencing woman's personal decision to have, or not have a baby, during preplanning stage, and its link to early maternal stress.

Expand *life course* research, which examines the link between chronic stressors and vulnerability to disease, especially as it relates to this target group and maternal health.

The father's voice is missing from much of the research, which suggests a devaluing of his worth with respect to BIM (Frey, 2008) or the sexist assumptions that only women's bodies are implicated in infant mortality. This study revealed a strong link between the existence of poor birth outcomes in the paternal family history, implicated in infant loss. More research is indicated in this area.

Further study on the connection between subsequent successful pregnancies, and active participation in bereavement/healing activities (i.e. counseling, ceremonies) following the infant loss, could yield important information for practice. Such research should include women and men.

In understanding the reasons for the disparity in black and white infant mortality rates, specifically related to middle class women, other comparative qualitative studies focused on the same target group (i.e.

women having successful birth outcomes) would generate important information.

Additionally, comparative qualitative studies between white and black middle class, educated married women who experienced infant loss, could yield important information in understanding the disparity in the IM rates.

Direct Service Implication:

The findings in this study suggest the need for Social Workers to possess knowledge of the historical and lived experiences of black women, and to integrate such knowledge into culturally sensitive practice with this client population. Increased understanding of coping mechanisms of the women and the health consequences of racism, will increase the effectiveness of approaches designed to reduce stress.

For Social Workers involved in pregnancy planning, paternal involvement should be encouraged, and paternal family history should be an added area for exploration.

Women should be screened for spousal abuse with inquiry being direct and clear.

Questions relating to events, situations, people, job and finances providing the larger context of life for the woman during the preplanning phase and during pregnancy, should be explored for the identification of

targeted interventions and education. It is important that professionals have candid conversations about the ability to take time off, finances, relating such factors to stress, which is implicated in adverse pregnancy outcomes.

Stress, as a factor implicated in BIM was prominent in the pregnancy stories shared by the women in this study, which corroborates research findings. The experiences of stress largely related to psychosocial issues; and the consequences of stress are largely medical. Helping women understand the effects of stress on their unborn fetus, to monitor stress, and to build on healthy coping mechanisms in dealing with stress, are targeted strategies Social Workers can provide in improving infant outcomes during pregnancy and pre-planning stages.

An increase in the professional alliances between Social Workers and Obstetricians could provide a holistic approach in identifying areas for needed intervention during pregnancy.

Helping and encouraging women to demand clear answers and possibly more aggressive medical interventions by their physicians, especially in light of medical complaints, is an area Social Workers should address.

In this study, several of the women were also experiencing mental health issues. As discussed, black women do not readily avail themselves to needed mental health services. Therefore, Medical Social Workers and Social Workers involved in pregnancy planning services, should explore

for the presence of mental health problems, and make appropriate referrals with follow-up and encouragement.

An important observation was the willingness of the women, once engaged in this project, to share the most intimate details of their pregnancy story with researcher. The experience seemed cathartic for all of the women who appreciated the fact that someone valued their experience enough to listen from the very beginning of their pregnancy story the end. This approach would seem to have value in the bereavement process for women who have experienced a pregnancy loss.

Education

A different approach to education on the issue of BIM, for this population, appears indicated. The fact that the majority of the women in this study had no prior knowledge of the problem of BIM, and the issues attached to BIM, points to the need for more concentrated efforts in relation to education, or could suggest that the current educational approaches are not working for middle-upper class black women. Social Workers may find it more effective to use natural settings (i.e. churches, sororities, self-help groups, and professional membership organizations) to ensure that a broader base of black women receive needed education and resource information in relation to BIM. Social networking media is used extensively by this population and could be effective for targeted messages. For example, DID YOU KNOW messages (i.e. stress can cause

you to have a poor pregnancy outcome) and then provide links to websites for specific information.

Collaborating with physicians for training purposes on the kind of information women are seeking, and the kind of information they (physicians) need from their patients, in order to better align communication to match the needs of the patient, is indicated.

Sensitivity training in relation to physicians' attitudes about BIM, and how such attitudes influence types of intervention and quality of patient care is also indicated.

Advocacy

Health disparities, across all medical specialties is demonstrated by a vast amount of research comprehensively captured in the Institute of Medicine's Report (2003) on confronting racial and ethnic disparities in health care. BIM represents one of the most significant health disparities experienced by black- American women. Social Workers have an important role to play in redressing the problem of BIM, and health disparities in general. The effectiveness of Social Workers' role starts in understanding the issues attached to BIM, and serving as patient advocates, and having a voice on policy matters directed toward removing health care disparities.

The current political/social and economic climate signals that we pay close attention to the lives of black American women, who are already

taking on more of the financial burden for their families; increasingly assuming the role of breadwinner (Shriver, 2009). There are social conditions, which are precursors for disease evident in the current political/social discourse in America, creating a threatening climate for blacks and other minorities, which produces stress. The research findings discussed in this paper on the deleterious effects of stress on the unborn fetus, and the sources of stress, suggests that we can anticipate an increase in the rate of BIM rate during this current period, directly attributed to a palpable sense of racism, which produces stress. It is important that Social Workers are part of consorted efforts to counteract the negative and dangerous loud voices.

Appendix A

Informed Consent

Black Infant Mortality among Middle-Class Black AmericanWomen:Personal Pregnancy Stories

Lisa Paisley-Cleveland is a Doctoral Student at the Graduate Center, City University of New York, Department of Social Welfare, PhD program at New York Hunter College. She is conducting doctoral research on the disparity between white and black infant mortality rates, with specific focus on Black Middle-Class American born women. Through oral interviews with women about their personal pregnancy stories, she hopes to uncover material that will deepen our understanding on the reasons for this persistent disparity.

You have been identified as a possible participant because you are a self-identified Black American born woman who has lost an infant. Participation in this study is completely voluntary.

You are being asked to participate in an in-person face-to-face interview with the researcher. The interview will last approximately 2.5 hours. During the interview you will be asked questions about your pregnancy history including prenatal care, your relationships with spouse/companion, family, friends and doctor, positive and/or problematic events, interventions surrounding your pregnancy and loss, quality of medical care, and any other information you may feel is important, including your thoughts on what happened. You may request to take a break at anytime during the interview.

Approximately 20 to 25 women will be interviewed for this study. The interview may take place in your home, or a suitable location convenient for you. Subsequent contacts may occur via telephone for follow-up questions and/or clarification in relation to information collected during the interview.

There are no direct benefits to you for your participation in this study. However, participating in this study may provide invaluable information about the problem of BIM for professionals who work with woman like you. You may experience some level of discomfort during the interview as you recall this difficult event. You may at any time withdraw your consent and discontinue participation. You do not have to answer any questions you do not want to answer. You will receive a list of resources in the event you feel you would like to pursue help or obtain more information about Black Infant Mortality (BIM).

The researcher will audiotape the interview with your permission, and you will be given a separate form to sign if you agree. No one but the researcher and her dissertation advisor will listen to the tape. The tapes will use identifying codes. Your name will not appear on the transcripts. Tapes will be destroyed after interviews are transcribed. No personal identifiers can be linked to the data. All records pertaining to this research will be kept in the researcher's home office in New Jersey in a locked file cabinet, and computer files will be safeguarded by a password. Upon completion of this study, the paperwork will be stored in a locked file cabinet for up to three years, after which time all original completed surveys will be destroyed. As long as the data exists, it will be kept secured. The information will be used to produce a doctoral dissertation and the researcher may seek publication for articles in professional journals. All identifying information about you and others who participated will be omitted or disguised.

The researcher is mandated to report to the proper authorities suspected child abuse, and any indications that you are in imminent danger of harming yourself or others.

If you have any questions, please feel free to contact Lisa Paisley-Cleveland., Researcher at (908) 672-1253 or Dr. Miriam Abramowitz, Dissertation Advisor at (212) 452-7106. If you have questions regarding your rights as a subject, or you feel you have been harmed as a result of your participation in this research, you should contact the Hunter College IRB Office at (212) 650-3053.

I have read (or have read to me) the contents of this consent form. I have been encouraged to ask questions. I have received answers to my questions. I willingly agree to participate in the research study described in this form. I have received (or will receive) a copy of this form for my records and future reference.

Signature of Participant _____ Date _____

Name of Participant (printed) _____

Signature of Researcher _____ Date _____

Name of Researcher (printed) _____

Appendix B

INTERVIEW GUIDE

Thank you again for agreeing to participate in this study. As I mentioned, many women like you, who have suffered the loss of their infant do not realize that Black Infant Mortality is a significant problem in the US that researchers are trying to understand. It is my hope that in spending time with you and others like you, this study might yield information, which will help us gain a deeper understanding as to why so many Black-American women are losing their infants before the age of one. Again, please understand that you do not have to answer any question that you do not wish to answer.

1. I would like to begin our conversation by talking about the beginning stage of your pregnancy. Please share with me how you felt when you first thought you were pregnant.

Probes: Was your pregnancy planned or unplanned? Was this your first pregnancy? How long after when you first thought you were pregnant did you confirm that you were pregnant? How was it confirmed? Who was the first person you told? What was their reaction?

2. Please describe any events, circumstances and/or people that stand out during this period.

3. At what point in your pregnancy did you decide to seek pre-natal care?

Probes: What made you decide to go at that time? Was it the same period you used in seeking pre-natal care for prior pregnancies?

4. OK. So in securing prenatal care how did you go about selecting your doctor?

Probes: Was race, gender, age, years of experience, location, insurance factors you considered?

5. Tell me about your first appointment; how did things go?

Probes: Were you pleased with the initial report provided by your doctor?

How often did you go to the doctor after this first visit?

6. Did someone accompany you on your first prenatal care visit?

Probes: Did you talk with this person about how you felt about this visit?

7. Following your initial appointment, you were seen __ times during the course of your pregnancy. During these visits, did you feel that you had formed a relationship with your doctor?

Probes: Were you able to comfortably communicate with your doctor?

Did you ask questions? Did you understand your doctor? Were you satisfied with responses to your questions? Were there any issues

related to your doctor's style, office staff, hours of operation, etc. that concerned you?

8. Did you seek any emergency and/or other medical care due to a problem(s) during the course of your pregnancy?

Probes: When? How did you feel about your doctor's response to your medical emergency or problem/complaint? How was it resolved?

9. Overall, how do feel about the quality of care you received during the course of your pregnancy?

Probes: What are your thoughts about your doctor's race and the role it played in your care? What about other office staff and other medical professionals and the issue of race? Do you feel that your race played a role in the quality of care you received?

OK. Thank you. We have now reached the halfway mark of the interview. I would like us to turn toward understanding how your pregnancy affected other areas of your life.

10. During your pregnancy, how were things going on your job, in your relationship with your husband, and family?

Probes: Can you recall any situations that were particularly pleasing or stressful?

11. Overall, how would you describe your disposition during your pregnancy?

Probes: Was your attitude the same as it was prior to your pregnancy, or did you notice a difference?

12. In your daily life did you continue to do the same things that you did prior to learning that you were pregnant? Did you notice any

changes, or did you implement any changes in your daily life patterns during your pregnancy?

Probes: Work schedule changes(reasons), sleep patterns, eating habits, significant change in diet, significant weight gain or loss? Did you do any traveling or attend any large functions during the last trimester of your pregnancy?

13. Thank you. OK. I am interested in understanding what happened on the day of your lost? How did things unfold?

Probes: Where were you? What year, month and day was it? What was the time? Who was with you?

14. What explanation was provided by your doctor?

15. As you look back are there questions that you now wonder about that you did not give much credit to before?

Probes: Do you have any, thoughts or feelings about why it happened?

16. Did you seek any kind of counseling after this event?

17. If so, did you find it helpful?

18. Do you have any advice to share?

19. What is the most valuable thing learned?

Appendix C

Biographical Information Chart

<i>Pseudonym</i>	<i>Education</i>	<i>Profession</i>	<i>Age</i>	<i>Spouse/ Profession</i>	<i>Age</i>	<i>Tri- mester of loss</i>	<i># Children Prior to Loss</i>
Yvonne	Masters	School Admin.	33	Scientist	33	2	2
Dorothy	MD	Physician	32	Physician	35	3	0
Alana	Masters	Counselor	30	Sales	29	3	2
April	Masters	Counselor	30	Business Owner	35	2	3
Willeta	College grad	Exec. Marketing	34	Music Producer	34	2	1
Freddie	College grad	Manager/ Tech	31	Manager Transport	32	3	0
Tina	College grad	Mental health professional	33	IT Specialist	34	3	1
Linda	Masters	Admin.	34	Manager/ Tech	34	3	1

Appendix D

Glossary

- **Infant Mortality (IM):** The death of an infant before his or her first birthday.
- **Black Infant Mortality (BIM):** The death of infant born to black women who die before their first birthday.
- **Gestation:** The nine-month period of pregnancy from conception to birth.
- **Low Birth Weight (LBW):** Babies born weighing less than 5 pounds, 8 ounces (2,500 grams) are considered low birth weight.
- **Neonatal:** The first 28 days of an infant's life.
- **Perinatal:** The 20th to 28th week of gestation and ends 1 to 4 weeks after birth.
- **Prematurity:** (less than 37 weeks gestation) and too small (less than 2,500 grams)

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